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An exploration of caregiver burden and positive gain in dementia, and development of an Acceptance and Commitment Therapy group intervention.

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Doctorate in Clinical Psychology

May, 2016

Word Count: 29,330

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Thesis Abstract

Background

Dementia has been a global priority for over a decade, with a recognition that it presents a growing challenge for all those directly affected, as well as for health and social care services. For those who are caring for a relative at home, carer burden has been found to be predictive of physical and mental health problems, and can impact on the decision to place a relative in fulltime residential care. Gaining a fuller understanding of factors that impact on caregiver burden may help inform the development of effective interventions for this population.

This thesis comprises a systematic review of the literature on individual behavioural and psychological symptoms of dementia (BPSD) and their impact on carer burden, a cross-sectional study of one hundred and ten dementia caregivers, exploring the impact of executive functioning deficits, and potential mediating mechanisms, on carer burden and positive gain, and a development and feasibility study of an Acceptance and Commitment Therapy (ACT) group intervention for dementia caregivers.

Systematic Review

Twenty-one studies measured the association between at least one individual symptom, or symptom cluster, and carer burden, and are included in the review. All studies found at least one symptom to be significantly associated with burden. However, due to the heterogeneity of studies in this field, there was insufficient evidence to establish whether any symptoms are more closely associated than others. Issues regarding the conceptualisation of burden and measurement of BPSD are highlighted and suggestions for addressing this in future studies proposed.

Method

One hundred and ten dementia caregivers completed five self-report questionnaires as part of a cross-sectional design, aiming to explore the role of executive functioning deficits, dementia management strategies and experiential avoidance in

the development of carer burden and positive gain. Drawing on these findings, a group intervention, based on ACT, was developed and delivered to twenty-three dementia caregivers. Data on attendance, attrition and qualitative feedback was collected as an indication of acceptability, and a quasi-experimental design, involving four pre, post and follow-up measures was employed to provide preliminary data on effectiveness. The measures used in both studies were the Dysexecutive Questionnaire (DEX) (study 1 only), Zarit Burden Interview (ZBI), Positive Aspects of Caregiving Questionnaire (PAC), Dementia Management Strategies Scale (DMSS) and Experiential Avoidance in Caregiving Questionnaire (EACQ).

Results & Conclusions

In study one, executive functioning deficits were found to account for most variance in burden. The use of negative management strategies and Active Avoidant Behaviour (a subscale of the EACQ), were also associated with higher levels of burden, while positive management strategies were associated with positive gain. The results suggest that management strategies and experiential avoidance could be potential mediating mechanisms in the development of carer burden, and so were targeted in the ACT group intervention in study two.

Findings from study two indicate that the group intervention was feasible and acceptable to caregivers, with subjective change reported in understanding of behavioural changes in the care-recipient, ability to handle negative emotions and valued living. Suggestions are made regarding alternative outcome measures for future studies in order to capture participants' experience more fully, as there was little statistically significant change in this study. Suggestions are also made regarding future directions for the intervention.

Terminology

The term ‘caregiver’ is used throughout this thesis to refer to a person who has identified themselves as providing regular care on an unpaid basis to a person with dementia who is residing at home. The term is intended to cover a spouse, partner, child, other relative or friend and supporter.

**A systematic review of the association between
individual behavioural and psychological
symptoms in dementia and caregiver burden**

Word count: 8080 (excluding abstract, tables and references)

Abstract

Background

The association between behavioural and psychological symptoms of dementia (BPSD) and the development of carer burden has been well established in the literature. However, it is not clear whether there are individual symptoms or clusters of symptoms that are particularly burdensome for caregivers. Such a finding would enable more focussed carer interventions to be developed.

Methods

A systematic review of the available literature was carried out to determine whether any specific symptom or cluster of symptoms was most closely associated with carer burden. In addition, the categorisation of behavioural symptoms, conceptualisations of burden and methods of measurement employed were examined, and quality of the studies appraised.

Results

Twenty-one studies measured the association between at least one individual symptom, or symptom cluster, and carer burden, with all studies finding at least one symptom to be significantly associated with burden. The majority of studies were of fair to good quality. However, there was considerable heterogeneity in focus, analysis, recruitment and measurement of behaviour and burden, and so comparison across studies was not possible.

Conclusions

Due to the heterogeneity of studies in this field, there was insufficient evidence to establish whether any symptoms are more important than others in the development of carer burden. In addition, there appears to be little consensus across studies regarding the conceptualisation of burden or measurement of BPSD. Future research could helpfully focus on clarifying the dimensions of carer burden and the mechanisms by which BPSD impact negatively on caregivers to inform the development of effective interventions.

Introduction

Background

Dementia has been a priority in the UK and internationally for over a decade, with a recognition that it presents a growing challenge for all those directly affected, as well as for health and social care services. By 2030 it is projected that there will be approximately 74.7 million people living with dementia across the globe (Prince et al., 2015). In 2014, 38% of people with dementia in the UK were living in full time residential care (Prince et al., 2014). This comes at a cost to services, but also at a financial and emotional cost to families.

For those who are able to continue caring for their relative at home, carer burden has been found to be predictive of depression and anxiety in caregivers (Cooper et al., 2008), greater risk of physical health problems (Pinquart & Sorensen, 2007) and increased mortality (Schulz & Beach, 1999).

Both behavioural problems and carer burden have been found to be predictive of caregivers' decision to place a relative in residential care (Spitznagel et al., 2006), and so have been the focus of much research in the field.

Behavioural and Psychological Symptoms of Dementia (BPSD)

The term Behavioural and Psychological Symptoms of Dementia (BPSD) came into use in 1999, following a consensus conference organised by the International Psychogeriatric Association (IPA) to discuss the need for research into such symptoms, their underlying causes, impact on individuals, families and society, and potential interventions (Finkel, 2000). Over the last twenty years a great deal of research has been carried out in this area and at least 83 instruments now exist to measure BPSD (Van der Linde et al., 2014). In their review of BPSD measures, Van der Linde et al. highlight some problematic issues, such as the difference in the description of some symptoms across measures (e.g. depression), the drawback of predominantly carer report measures, which are likely to focus on more troublesome behaviours (e.g. irritability), and the overlap of some symptoms (e.g. apathy and depression).

The impact of BPSD on caregivers has been widely studied, but with the majority of studies using a total score derived from a measure such as the Neuropsychiatric Inventory (NPI) or BEHAVE-AD (Cummings et al., 1994; Reisberg et al., 1987) rather than measuring the effects of individual symptoms. Given the heterogeneity of BPSD measures and their different foci, there is some doubt as to whether these findings can be compared across studies (Shah et al., 2005) and whether, with such poor specificity, the findings can be clinically useful. For example, using the NPI, a similar total score could result from a combination of difficulties in areas of depression, apathy and sleep, or difficulties with irritability, agitation and delusions. However, the intervention required would clearly be different.

Instruments designed to measure specific individual behaviours have also been widely utilised in the literature. By definition, these have good specificity and so can be more helpful clinically. However, for research purposes, comparability with other measures may be problematic due to the level of detail involved. For example, measures such as the Cohen-Mansfield Agitation Inventory (CMAI: Cohen-Mansfield et al., 1989) or the Apathy Evaluation Scale (AES; Marin et al., 1991) consist of many items assessing one symptom in detail. They may, therefore, capture symptoms that would not have been picked up by a single item on a global scale such as the NPI.

The link between BPSD and negative caregiver outcomes has now been well established (e.g. Ballard et al., 2000). However, in order to understand the complexity of this relationship and potentially develop effective interventions, it will be helpful to understand more fully the effects of individual symptoms or clusters of symptoms on carer burden.

Carer burden

The concept of “carer burden” was largely introduced into the literature by Zarit et al. (1980), with their description of the development of the original Zarit Burden Interview (ZBI), covering areas including caregivers’ physical health, psychological well-being, social and financial stresses and the relationship between caregiver and care-recipient. Due to the increasing numbers of unpaid caregivers providing care to older relatives with dementia, and the consequences this can have on their well-being

and that of the person for whom they are caring, this area has subsequently been highly researched and various models proposed to conceptualise burden.

Montgomery et al. (1985a) highlighted the importance of distinguishing between objective and subjective burden in studying caregivers' experience. Objective burden is understood as referring to the characteristics of the care-recipient, their cognitive and behavioural symptoms and the practical impact of their care needs e.g. in terms of time and money, while subjective burden refers to the caregiver's appraisal of the situation and their emotional response. This study found different correlates relating to each type of burden, indicating that understanding the type of burden experienced by caregivers is necessary in order to intervene effectively (Montgomery et al., 1985a).

The distinction between objective and subjective burden has been widely supported in the literature, and has been incorporated into more complex theories to describe carer stress. One of the most influential of these is the stress process model (Pearlin et al., 1990). In this model, both objective indicators, such as cognitive and behavioural symptoms, and subjective indicators, such as the burden felt by the caregiver and the change in nature of caregiver/care-recipient relationship, are conceptualised as primary stressors. According to this model, these then lead to intrapsychic strains, such as impact on self-esteem and mastery, feelings of being trapped and loss of self, ultimately resulting in negative outcomes for caregivers, such as depression, anxiety and impact on physical health.

Although the stress process model distinguishes between objective and subjective burden, both types of burden are seen as primary stressors. Others, however, have proposed that subjective burden is more akin to the intrapsychic strains in Pearlin's model (Bastawrous, 2013). Yates et al. (1999) proposed an alternative stress model, in which burden is seen as a secondary appraisal of the more objective primary stressors of cognitive status, functional dependency and behavioural problems, which then impacts on caregiver well-being and depression.

Despite the ongoing theoretical debate around the nature of burden, the concept still remains loosely defined, with much of the literature failing to provide any theoretical background or rationale for the use of burden as an outcome (Bastawrous, 2013).

Many of the most widely used burden measures do not clearly differentiate between objective and subjective burden, and the variation in focus across measures makes comparisons between studies problematic (Vitaliano et al., 1991).

An additional issue with the various stress and burden theories mentioned above is that there can be some overlap between concepts, such as low self-esteem, which can be considered either a component of carer burden, or a mediator in the stress process. This has led some researchers to propose that carer burden is more complex than simply objective and subjective aspects, and that it is multi-dimensional in nature. Several studies have explored this concept through factor analysis of responses to the widely used Zarit Burden Interview (Zarit et al., 1980). For example, Hebert et al. (2000) proposed a short version consisting of two factors: personal strain and role strain, while others (e.g. Ankri et al., 2005; Springate & Tremont, 2014) proposed that the measure comprises three factors, such as “impact on caregiver life” and “guilt”. Studies exploring these dimensions of burden have found that different caregiver and care-recipient variables are associated with each dimension of burden (Springate & Tremont, 2014), and therefore it may be important to measure specific dimensions of burden in order for effective targeted interventions to be developed.

Links between BPSD and carer burden

As described above, numerous studies have examined the association between BPSD and carer burden, and several have also explored the impact of individual symptoms on caregivers (Gallagher-Thompson et al., 1992, Ozel-Kizil et al., 2014). Few studies, however, have attempted to discover which symptoms are most burdensome to caregivers. In their review, Fischer et al. (2012) report psychosis as being the most common neuropsychiatric symptom associated with carer burden. However, their sample of studies was small, due to narrow search terms and time period, outcome measures included were highly heterogeneous, and quality and effect sizes were not reported.

In a more robust systematic review, Ornstein and Gaugler (2012) sought to determine: a) which BPSD are most commonly associated with caregiver burden and depression b) the mechanisms by which symptoms affect caregivers c) the role of timing of symptoms in the development of burden. Lack of consistent BPSD

categorization, heterogeneity of measures, small samples and lack of control for confounders were some of the main limitations this review found in the existing literature.

Study Aims

This review aims to update the review of Ornstein and Gaugler (2012), which included studies up to 2010, focussing on the outcome of burden only. As there has been a proliferation of research in carer burden over the past few years, it is expected that extending this review by five years will result in significantly more papers for inclusion. Firstly, this study aims to determine whether there is a specific behavioural/psychological symptom or cluster of symptoms most closely associated with carer burden in the existing literature, and to provide a critical appraisal of the literature. Due to the variation in definition/categorisation of behavioural symptoms and methods of measurement found across the literature, and the lack of consensus regarding the conceptualisation of carer burden, this review also aims to explore in detail the conceptualisation of behaviour and burden, and methods of measurement utilised, within the included studies.

Method

Protocol

A protocol for the systematic review was developed and registered with Prospero according to the guidelines published by the Centre for Reviews and Dissemination, University of York (CRD, 2009). The protocol included an outline of the research question, eligibility criteria, details of the population included and planned methods for data extraction and quality rating. The protocol is available at:

http://www.crd.york.ac.uk/PROSPERO_REBRANDING/display_record.asp?ID=CRD42015019235

Inclusion Criteria

It was decided that the review would include cross-sectional or longitudinal studies, dating from 1980 (the year the original Zarit Burden Interview (ZBI) was published) to the date of the final searches (4th January 2016). All studies had to include a statistical test on the association between individual behavioural and psychological symptoms of dementia, or clusters of symptoms, and carer burden. Trials of

interventions could also be included if such an analysis were carried out and reported at baseline. In order for the review to explore the use of “burden” as a construct in the literature, all studies had to conceptualise the outcome as “burden”, and use a measure reflecting this (e.g. ZBI, Caregiver Buren Inventory). Studies involving informal or unpaid caregivers of a person diagnosed with any form of dementia were included.

Exclusion Criteria

Studies involving paid caregivers or people living in residential care were excluded. Studies were also excluded if they reported behavioural and psychological symptoms as a total score only, or if the outcome measure reported was not burden, but a related construct, such as distress, strain or depression. Conference proceedings were excluded, if no full paper detailing the results was available after contacting authors. Any other studies for which only the abstract was available were excluded due to insufficient information. Unpublished dissertations and theses were excluded, as well as studies in languages other than English, due to the scope of this study.

Selection of Search Terms

Due to the proliferation of research in this area in recent decades, it was necessary to consider carefully the terms most likely to produce the relevant results in a literature search.

In order to find the most frequently used alternatives to “burden” in the literature, book chapters on the topic were consulted (e.g. Brodaty et al., 2005), as well as relevant policy documents (e.g. Scottish Government & COSLA, 2010) and previous reviews of carer burden studies. In addition, seminal articles in the field, such as Zarit et al. (1980) and Pearlin et al. (1990) were searched for further relevant terminology. It was found that the terms most commonly used interchangeably with “burden” were “stress”, “strain”, “burnout” and “distress”. Preliminary searches revealed that using “distress” as a search term yielded many results unrelated to burden, and incorporated depression and anxiety, which have been established as separate constructs to burden. As most of the relevant articles, which included “distress” as a descriptor, also included one of the other terms above, it was decided

to omit “distress” from the search terms. The final terms used for the “burden” construct were, therefore, “burden”, “stress”, “strain” and “burnout”.

In order to find articles measuring individual behavioural and psychological symptoms of dementia, it was necessary to include potential individual symptoms in the criteria. A preliminary search of the databases was carried out using only the search terms “behavioural symptoms” and “dementia”. The first 120 of these articles were searched to find the most frequently mentioned behavioural symptoms. These were: agitation/aggression; delusions/hallucinations; irritability/lability; disinhibition; apathy/depression/anxiety. These results were also borne out by consulting the NICE and SIGN guidelines on management of dementia and the Newcastle model for addressing stressed and distressed behaviour in dementia (NICE, 2006; SIGN, 2006; James, 2011). The inclusion of depression, anxiety and apathy (the equal 5th most frequently rated terms) in preliminary searches resulted in a number of articles well in excess of the scope of this study, and included many studies where mood related difficulties were not conceptualised as symptoms of dementia. Therefore, it was decided to use the first four most frequently rated BPSD only as search terms i.e. agitation/aggression, delusions/hallucinations, irritability/lability and disinhibition.

Search Strategy

The following databases were searched from 1980 to 4th January 2016: PsychInfo, Medline and Embase. The search terms used were: dementia OR Alzheimer* AND care* AND burden OR stress OR strain OR burnout AND behavior* OR BPSD OR agitation OR aggression OR delusions OR hallucinations OR irritability OR lability OR disinhibition. Hand searches of reference lists from existing reviews were also carried out.

Quality Assessment

A quality assessment rating tool for methodological appraisal of the studies was developed following the guidelines in SIGN 50: A guideline developer’s handbook (2015), the STROBE checklist (Von Elm et al., 2007) and Sanderson et al. (2007). Items included on the tool were also influenced by the specific aims of this review, i.e. “rationale for and operationalisation of burden”, and “theoretical basis for

clusters /subscales of behaviour used”. Items were rated as 2: well covered, 1: adequately covered or 0:poorly or not covered, with a possible maximum score of 18 for each study. See Appendix 1 for Quality Assessment Tool. The total score for each study was then converted into a percentage and the methodological quality of each study was categorised as Good - $\geq 70\%$, Fair - $\geq 50\%$ or Weak $< 50\%$.

Nine of the included studies were selected at random and rated independently by a second researcher. Cohen’s Kappa was .77 ($p<.001$), indicating good inter-rater reliability. Items on which raters did not agree were resolved through discussion.

Results

Study Selection

After duplicates were removed, the search strategy yielded 4011 results, with an additional 19 results found through hand searching reference lists. Titles and abstracts were screened for inclusion against the eligibility criteria above. This resulted in 136 articles for which the full text was reviewed for inclusion in the final methodological review. Following this, 21 articles met the criteria for inclusion in the final review stage. The selection process is shown in the flowchart in Figure 1, based on the PRISMA guidelines (Moher et al., 2009). Reasons for exclusion of studies following review of full text are detailed in Appendix 2.

Study Characteristics

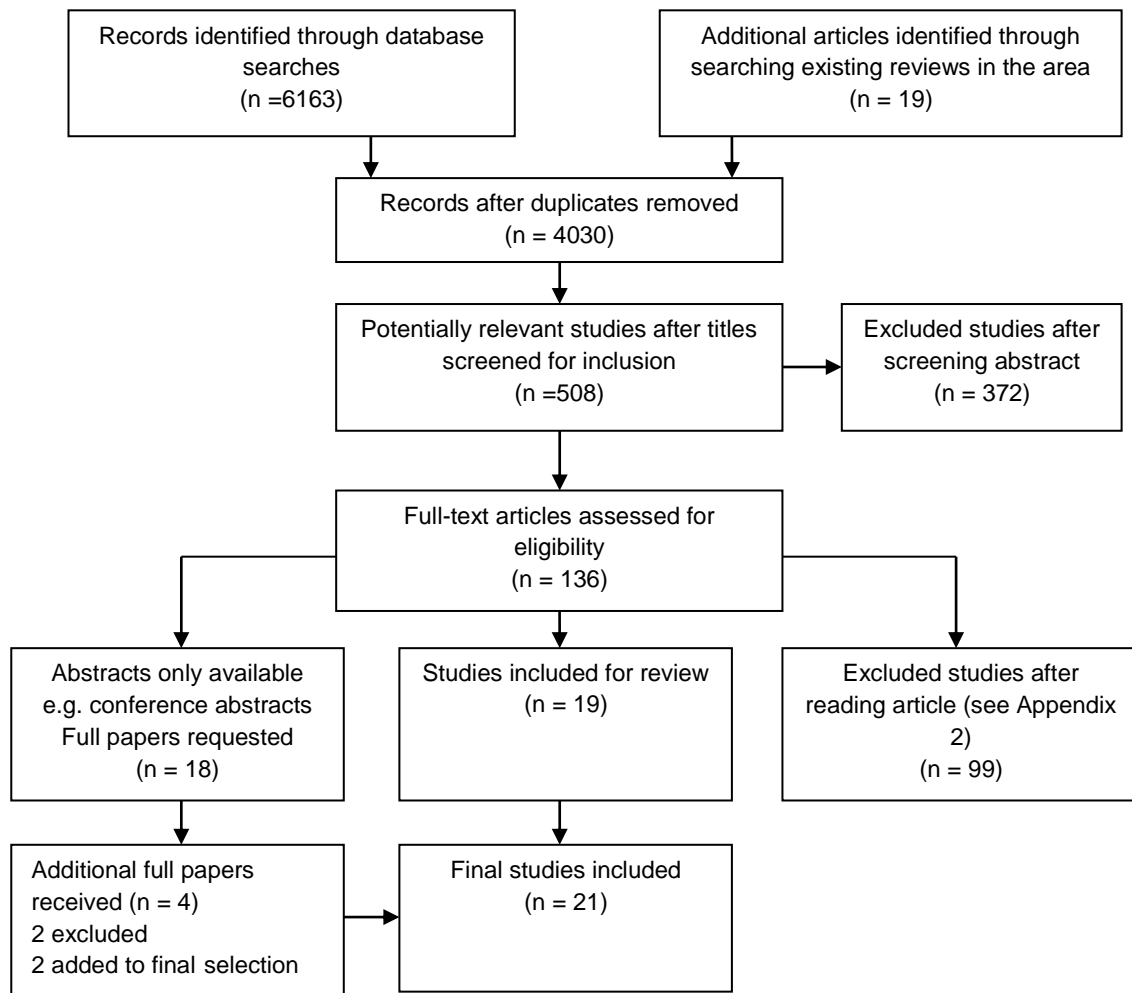
Data was extracted from the twenty-one included studies, using a standardised form. Results are shown in Table 1. Where correlation and regression analyses have both been carried out, only the correlation results are reported, as the current review is concerned with associations between BPSD and burden rather than predictors of burden.

Design and Focus

The majority of the studies adopted a cross-sectional design with carer burden as the primary outcome measure. Several of the studies also included other caregiver outcomes. Five included depression, one included “distress” (Donaldson et al., 1998) and one included both depression and anxiety (Lou et al., 2015). In all cases, the

results indicated that burden represents a separate construct, distinct from “distress”, depression or anxiety.

Figure 1: Flow diagram showing article selection process



Two studies employed a longitudinal design to explore the course of dementia related symptoms over time and their relationship to burden (Berger et al., 2005; Gaugler et al., 2010). Kamiya et al. (2014) were also interested in the relationship between symptoms and carer burden through the different stages of dementia. However, they addressed this through a cross-sectional design, subdividing their 881 participants into clusters, according to dementia severity. Pruchno & Resch (1989) used a similar method, clustering their 262 participants according to levels of severity of each behavioural symptom.

Guevara et al. (2015) utilised an experimental design to measure the impact of theory of mind impairment on carer burden, also including data from neuro-imaging to indicate the areas of the brain most likely to be involved. Yan and Kwok (2010) was the only study in this review which proposed burden as a mediator, utilising a cross-sectional design to explore whether the effect of agitated behaviour on caregiver abusive behaviours is mediated by carer burden.

Two further studies in which burden was not the main outcome measure were those of Weinstein et al. (1991), where the association of behavioural symptoms and burden was measured at baseline, as part of a randomised controlled trial of a cholinestarese inhibitor, and Riviere et al. (2002), who measured burden as a possible predictor of aversive feeding behaviour.

Regarding behaviours measured, two thirds of the studies employed a global measure and were exploratory in nature, aiming to establish which behavioural symptoms were most impactful. Of the other studies, two focussed specifically on the symptom of agitation (Yan & Kwok, 2010; Ozel-Kizil et al., 2014), one on feeding behaviours (Riviere et al., 2002), one on sleep and nocturnal behaviours (Kim et al. 2014), and three on “frontal behaviours”, including theory of mind and impaired awareness (Rymer et al., 2002; Davis & Tremont, 2007; Guevara et al., 2015). One study (Victoroff et al., 1998) utilised both a global measure and a specific measure of agitation.

Sampling

Both community and clinic samples were fairly equally represented in the studies, with two studies failing to report this fully (Ozel-Kizil et al., 2014; Guevara et al., 2015). Recruitment procedures were mixed, with some community samples recruited from support groups (e.g. Pruschno & Resch, 1989), while others were identified through more universal approaches, such as insurance plan lists (e.g. Chappell & Penning, 1996), thereby reducing potential bias in the sample. Where gender of the caregiver was reported, there was a strong bias towards female caregivers, as is the case in caregiving literature in general. Reported percentages of female caregivers in the studies ranged from 57% (Donaldson et al., 1998) to 79% (Chappell & Penning, 1996), with seven studies reporting their sample as over 70% female.

Table 1: Overview of selected studies

Study	Design	Country	Population (clinic/ community)	Diagnosis	Sample Size	Behaviour Scale Used	Burden Scale Used	Statistical Analysis used	Behaviours measured and significance	Effect sizes/available statistics for significant variables
Pruchno & Resch, 1989	CS	USA	Community – spouses only	AD	262	Measure developed for the study	Single item Indexing perceived burden	ANOVA	Forgetful* , asocial* and disoriented*	Forgetful (F=3.64,df=4,p<.01) Asocial (F=3.52,df=4,p<.01) Disoriented (F=3.00,df=3,p<.05)
Weinstein et al., 1991	RCT	Netherlands	Clinic	AD	12	Subscales of the Dutch Behaviour Rating Scale for Psycho-geriatric Inpatients	Dutch burden questionnaire	Spearman rank correlation	Apathetic, non-social, rebellious, disoriented* , restless, dependent*	Disoriented (r=.67,p<.01) Dependent (r=.73,p<.01)
Chappell & Penning, 1996	CS	Canada	Community	Dementia	327	DBD	ZBI	Multiple Regression	Aimlessness* aggressiveness* forgetfulness* lack of cooperation, restlessness/agitation* , incontinence, apathy* inappropriate sexual behaviour	Aimlessness (β =0.22; p<.001) Aggressiveness (β =0.17; p<.001) Forgetfulness (β =0.38, p<.001) Restlessness (β =0.14; p<.01) Apathy (β =0.24; p<.001)
Donaldson et al., 1998	CS	UK	Clinic	AD	100	MOUSEPAD	Subjective burden scale derived from GSS for this study	Correlation and regression analyses	Disturbance in walking* , eating* , sleep* , sexual behaviour, aggression* , laughing/crying; delusions, hallucinations, misidentifications, reduplications	Walking disturbance (r=.42,p<.01) Eating disturbance (r=.24,p<.05) Sleep disturbance (r=.22,p<.05) Aggression (r=.36,p<.01)

Study	Design	Country	Population (clinic/ community)	Diagnosis	Sample Size	Behaviour Scale Used	Burden Scale Used	Statistical Analysis Used	Behaviours measured and significance	Effect sizes/available statistics for significant variables
Victoroff et al., 1998	CS	USA	Clinic – spouses only	Dementia	35 (25 for BEHAVE – AD)	Interview & CMAI (& BEHAVE-AD for 25 participants)	ZBI	Correlation and regression analyses	Agitation* (CMAI total score) Subscales: physical aggression*, verbal aggression*, nonaggressive agitated behaviour* Agitation* (BEHAVE-AD 13-18) Interpersonal violence* (from items on both scales combined)	Agitation (CMAI) (r=.59,p<.001) Physical Aggression (r=.51,p<.01) Verbal aggression (r=.44,p<.01) Nonaggressive agitation (r=.41,p=.01) Agitation (BEHAVE-AD) (r=.66, p<.001) Interpersonal violence (r=.45,p<.01)
Riviere et al., 2002	Longitudinal (baseline & 1 year follow up; baseline data only used)	Europe (France, Spain, Italy)	Clinic & Community	AD	224	CMAI (adapted), AFBI	ZBI	Correlation	Aversive feeding behaviour – baseline data only – not significant	N/A
Rymer et al., 2002	CS	USA	Clinic	AD	41	QDM (awareness measure); FrSBe	ZBI	Correlation and regression analyses	Impaired awareness*, Frontal systems behaviour*	Impaired awareness (r=.51,p<.002) Frontal systems behaviour (r=.59,p<.001)
Berger et al., 2005	Longitudinal (2 year period)	Germany	Clinic	Dementia	45	BEHAVE-AD; NOSGER	ZBI	Correlation	Psychotic symptoms, behavioral disturbances (activity & aggressiveness)* , diurnal rhythm disturbances, affective disturbances, anxiety*, social behaviour*, disturbing behaviour* (baseline data only used)	Behavioral disturbances (activity & aggressiveness) (r=.69, p<.01) Anxiety & phobias (r=.42, p<.01) Social behaviour (r=.46, p<.01) Disturbing behaviour (r=.39, p<.01)

Study	Design	Country	Population (clinic/ community)	Diagnosis	Sample Size	Behaviour Scale Used	Burden Scale Used	Statistical Analysis Used	Behaviours measured and significance	Effect sizes/available statistics for significant variables
Bedard et al., 2005	CS	Canada	Clinic	AD	557	DBRI	ZBI (role burden and personal burden)	Correlation and regression analyses	Difficult behaviours*, emotional behaviours*, psychotic behaviours*, repetitive behaviours*	Role Burden: Difficult behaviours (r=.55, p=.001) Emotional behaviors (r=.61, p=.001) Psychotic behaviors (r=.47, p=.001) Repetitive behaviors (r=.34, p=.001) Personal Burden: Difficult behaviours (r=.35, p=.001) Emotional behaviors (r=.47, p=.001) Psychotic behaviors (r=.35, p=.001) Repetitive behaviors (r=.29, p=.001)
Onishi et al., 2005	CS	Japan	Clinic & Community	Dementia symptoms (diagnosis not clear)	116	Original list compiled for the study	ZBI (+ single item to rate own sense of burden out of 100 correlations not reported in paper)	Multiple regression	35 individual behaviours measured: significant behavioural variables were disturbing conversation*, appears unhappy or depressed*, urinary incontinence*	Disturbing conversation (standardised β =0.294) Appears unhappy or depressed (standardised β =0.304) Urinary incontinence (standardised β =0.205)
Allegri et al., 2006	CS	Argentina	Clinic	AD	82	NPI	ZBI	Correlation	Delusions*, hallucinations*, agitation*, depression, anxiety*, euphoria, apathy, disinhibition*, irritability, aberrant motor behaviour*, nighttime behaviour disturbances*, changes in appetite and eating behaviour*	Anxiety (r=.57, p<.01) Nighttime behaviour disturbances (r=.48, p<.01) Hallucinations (r=.40, p<.01) Aberrant motor behaviour (r=.39, p<.01) Agitation (r=.30, p<.05) Changes in eating behaviour (r=.30, p<.05) Delusions (r=.29, p<.05) Disinhibition (r=.29, p<.05)

Study	Design	Country	Population (clinic/ community)	Diagnosis	Sample Size	Behaviour Scale Used	Burden Scale Used	Statistical Analysis Used	Behaviours measured and significance	Effect sizes/available statistics for significant variables
Davis & Tremont, 2007	CS	USA	Clinic & Community	Dementia	72	FrSBe	ZBI	Correlation and regression analyses	Frontal Systems Behaviour (FrSBe)	FrSBe (r=.53,p<.01)
Rocca et al., 2010	CS (used cluster analysis: psychotic/behavioral cluster; depressive cluster; minimally symptomatic cluster)	Italy	Clinic	AD	195	NPI	CBI	Multiple regression	Delusions, hallucinations, agitation* , depression, anxiety, euphoria-denial, apathy* , disinhibition, irritability, aberrant motor behaviour* , nighttime behaviour disturbances* , changes in appetite and eating behaviour (Psychotic/behavioral cluster – higher levels of burden overall, but no significant associations with specific behaviours)	Depressive Cluster: Apathy (d.f.=1,96, standardised β =.22, p=.02) Agitation (d.f.=1,96, standardised β =.41, p<.001) Aberrant motor behaviour (d.f.=1,96, standardised β =.21, p=.05) Minimally symptomatic cluster: Apathy (d.f.=1,71, standardised β =.39, p=.001) Nighttime behaviour disturbances (d.f.=1,71, standardised β =.27, p=.02)
Yan & Kwok, 2010	CS	Hong Kong	Community	Dementia	122	CMAI	ZBI	Correlation	Agitated behaviour*	Agitated behaviour (r=.42,p<.01)
Gaugler et al., 2010	Longitudinal (secondary data analysis)	USA	Community	Dementia	4545	MBPC	ZBI (short form)	Mixed effect model - regression	19 behaviours measured – all significant ($p \leq .01$). Strongest predictors of burden: dangerous to others* , anger* , combateness* , wakes caregiver at night* , dangerous to self*	Dangerous to others (B=1.99, e.s.=.30) Anger (B=1.90,e.s.= 0.30) Combateness (B=1.74; e.s.=0.27) Wakes caregiver at night (B=1.73,e.s.=0.27) Dangerous to self (B=1.68,e.s.=0.26)

Study	Design	Country	Population (clinic/ community)	Diagnosis	Sample Size	Behaviour Scale Used	Burden Scale Used	Statistical Analysis Used	Behaviours measured and significance	Effect sizes/available statistics for significant variables
Kamiya et al., 2014	CS	Japan	Clinic	AD subdivided into different stages of AD, based on MMSE scores	881	DBD	ZBI	Multiple regression	Behaviour disturbance*, verbal aggressiveness*, memory impairment, motor aggressiveness*, Incontinence*, apathy*	AD29-24: Behaviour disturbance ($\beta = .24, p < .01$); Motor aggressiveness ($\beta = .21, p < .05$); Apathy ($\beta = .33, p < .001$). AD23-18: Behaviour disturbance ($\beta = .19, p < .001$); Verbal aggressiveness ($\beta = .33, p < .001$); Incontinence ($\beta = .21, p < .001$); Apathy ($\beta = .13, p < .01$). AD17-12: Behaviour disturbance ($\beta = .22, p = .001$); Verbal aggressiveness ($\beta = .26, p < .001$); Apathy ($\beta = .17, p < .01$). AD11-0: Behaviour disturbance ($\beta = .48, p < .001$); Motor aggressiveness ($\beta = .23, p < .05$).
Kim et al., 2014	CS (secondary data analysis)	USA	Clinic	Dementia	60	CMAI; Sleep onset latency; ABI (observed nocturnal agitation behaviours)	ZBI	Correlation and regression analyses	Sleep onset latency; Researcher observation of nocturnal agitation behaviour; caregivers' self report of nocturnal agitation behaviours*	Caregivers' self report of nocturnal agitation behaviour (CMAI) ($r = .43, p < .01$)
Ozel-Kizil et al., 2014	CS	Turkey	Not reported	Dementia	49	CMAI	ZBI (subscales also used)	Correlation and regression analyses	Agitation*	Agitation and: ZBI total score ($r = .69, p < .001$)
Guevara et al. 2015	experimental	USA	Not reported	Bv-FTD	20	Faux-pas task	ZBI – single item	Correlation	Theory of mind impairment*	Theory of mind impairment (FP task) ($r = -.54; p < .01$)

Study	Design	Country	Population (clinic/ community)	Diagnosis	Sample Size	Behaviour Scale Used	Burden Scale Used	Statistical Analysis Used	Behaviours measured and significance	Effect sizes/available statistics for significant variables
Oh et al. 2015	CS	Korea	Clinic	PDD	48	NPI	ZBI & CBI (subscales of CBI also included in analysis)	Correlation	Delusions* , hallucinations* , agitation* , depression, anxiety* , euphoria-denial, apathy* , disinhibition* , irritability* , aberrant motor behaviour* , nighttime behaviour disturbances* , changes in appetite and eating behaviour*	Correlations with ZBI total score: Anxiety ($r=.58, p<.001$) Irritability ($r=.52, p<.001$) Disinhibition ($r=.51, p<.001$) Agitation ($r=.47, p=.001$) Aberrant motor behaviour ($r=.44, p=.002$) Hallucinations ($r=.44, p=.002$) Delusions ($r=.43, p=.001$) Apathy ($r=.41, p=.004$) Depression ($r=.36, p<.05$) Correlations with CBI total score: Delusions ($r=.50, p<.001$) Irritability ($r=.47, p=.001$) Anxiety ($r=.46, p=.001$) Agitation ($r=.45, p=.001$) Disinhibition ($r=.45, p=.001$) Hallucinations ($r=.37, p=.01$) Aberrant motor behaviour ($r=.34, p=.02$) Nighttime behaviour disturbances ($r=.03, p=.02$) Changes in eating behaviour ($r=.03, p=.03$)

Study	Design	Country	Population (clinic/ community)	Diagnosis	Sample Size	Behaviour Scale Used	Burden Scale Used	Statistical Analysis Used	Behaviours measured and significance	Effect sizes/available statistics for significant variables
Lou et al. 2015	CS	China	Clinic	AD	310	NPI – frequency rather than presence of behaviours used in analysis	ZBI	Correlation	Delusions* , hallucinations* , agitation* , depression* , anxiety* , euphoria- denial* , apathy* , disinhibition* , irritability* , aberrant motor behaviour* , nighttime behaviour disturbances* , changes in appetite and eating behaviour*	Apathy ($r=.34, p<.001$) Irritability ($r=.33, p<.001$) Aberrant motor behaviour ($r=.32, p<.001$) Nighttime behaviour disturbances ($r=.31, p<.001$) Anxiety ($r=.30, p<.001$) Depression ($r=.30, p<.001$) Delusions ($r=.29, p<.001$) Agitation ($r=.29, p<.001$) Hallucinations ($r=.27, p<.001$) Euphoria ($r=.18, p<.001$) Changes in eating behaviour ($r=.17, p<.01$) Disinhibition ($r=.16, p<.01$)

Abbreviations: CS = Cross-sectional; e.s.=effect size; AD = Alzheimer's Disease; Bv-FTD = Behavioural variant fronto-temporal dementia; PDD = Parkinson's Disease Dementia; DBD = Dementia Behaviour Disturbance Scale; ZBI = Zarit Burden Interview; MOUSEPAD = Manchester and Oxford Scale for Psychopathological Assessment in Dementia; GSS = Gilleard's Strain Scale; BEHAVE-AD = Behavioural Pathology in Alzheimer's Disease; CMAI – Cohen-Mansfield Agitation Inventory; AFB1 = Aversive Feeding Behaviour Inventory; QDM = Questionnaire Discrepancy Measure; FrSBe = Frontal Systems Behaviour Scale; NOSGER = Nurses' Observation Scale for Geriatric Patients; DBRI = Dysfunctional Behaviour Rating Instrument; NPI = Neuropsychiatric Inventory; CBI = Caregiver Burden Inventory; MBPC = Memory and Behaviour Problems Checklist; MMSE = Mini Mental State Examination; ABI = Agitation Behaviours Index.

* indicates significance at $p<.05$

With regard to diagnosis, ten of the studies chose to focus on caregivers of people with a diagnosis of Alzheimer's /probable Alzheimer's disease (AD) only. Eight of the studies were open to all dementia diagnoses, one was focussed on behavioural variant fronto-temporal dementia (Guevara et al., 2015), one on Parkinson's Disease dementia (Oh et al., 2015) and one was unclear as to diagnosis (Onishi et al., 2005).

Measures used

Behaviour measures

A wide variety of behaviour measures were employed. As mentioned above, two thirds of the studies adopted a global measure of behaviour, with seven different validated measures used, while two of the studies used a global measure developed specifically for the study (Pruchno & Reisch, 1989; Onishi et al., 2005). The most frequently used was the Neuropsychiatric Inventory (NPI: Cummings et al., 1994), used by Allegri et al. (2006), Rocca et al. (2010), Lou et al. (2015) and Oh et al. (2015). This was followed by the Behavioural Abnormalities in Alzheimer's Disease Rating Scale (BEHAVE-AD: Reisberg et al., 1987), used in two studies (Victoroff et al., 1998; Berger et al., 2005) and the Dementia Behaviour Disturbance Scale (DBD: Baumgarten et al., 1990), used by Chappell & Penning (1996) and Kamiya et al. (2014).

Of those studies measuring specific types of behaviour, the Cohen-Mansfield Agitation Inventory (CMAI: Cohen-Mansfield, 1986) was used in five studies, the Frontal Systems Behaviour Scale (FrSBe: Grace & Malloy, 2001) was used in two, and one study used the Aversive Feeding Behaviour Inventory (AFBI: Blandford et al., 1998).

All of the above measures rely on caregiver report of behaviours, which introduces an important potential bias, particularly in this type of study, as it is likely that the most burdened caregivers will also score their relative higher on measures of behavioural difficulties. Only three studies used any other type of measure. Rymer et al. (2002) used the Questionnaire Discrepancy Measure (Green et al., 1993), which uses a measure of the discrepancy between caregiver and care-recipient report of memory problems as an objective measure of awareness. Kim et al. (2014) used an observational measure of care-recipients' nocturnal agitation behaviours in their

study. They found that there was no direct correlation between caregivers' perception of nocturnal agitation behaviour and the observed measure, further highlighting the potential issues with reliance on caregiver reports. Finally, Guevara et al. (2015) employed a "faux-pas task" as an objective measure of theory of mind impairment in care-recipients with fronto-temporal dementia.

Burden measures

The overwhelming majority of studies (eighteen) employed the Zarit Burden Interview (ZBI) as an outcome measure. Two of these studies (Guevara et al., 2015; Pruchno et al., 1989) used only one item of the ZBI as a measure of burden (i.e. "overall how burdened do you feel in caring for your relative/spouse?"). The majority used the total ZBI score as an outcome variable, with two studies using established subscales as the outcomes. Bedard et al. (2005) used the subscales of "personal strain" and "role strain" (Hebert et al., 2000), while Ozel-Kizil et al. (2014) used five factors originally proposed by Ozlu et al. (2009): "mental irritability and subjective deterioration of living"; "nervousness and feeling restricted"; "deterioration in social relationships"; "economic burden"; "dependency".

Of the remaining studies, Weinstein et al. (1991) used a Dutch burden questionnaire, based on the ZBI. Donaldson et al. (1998) derived an index of subjective burden from items on the Gilleard Strain Scale (GSS: Gilleard, 1984). Rocca et al. (2010) and Oh et al. (2015) both used the Carer Burden Inventory (CBI: Novak & Guest, 1989). Rocca et al. used the total CBI score as the outcome measure, while Oh et al. used subscales of the CBI ("time-dependence burden", "developmental burden", "physical burden", "social burden" and "emotional burden") and the total score of the ZBI.

Summary of findings

This review aimed to discover whether there is a specific behavioural/psychological symptom or cluster of symptoms most closely associated with carer burden. Due to the heterogeneity in focus, analysis, recruitment and measurement of behaviour and burden, it was not possible to carry out a meta-analysis of the results. In addition, it would not be meaningful to attempt to draw conclusions regarding the symptoms which are most burdensome to caregivers, given the diversity of these studies.

However, the following is a summary of the main findings, as well as issues and discussion points highlighted.

BPSD associated with burden

Eleven of the twelve studies employing a global measure of BPSD, in which agitation and/or aggression was measured, found this to be significantly associated with carer burden. In addition, the two studies which focussed specifically on agitation (Yan & Kwok, 2010; Ozel-Kizil, 2014) also found this association to be significant. Disinhibition was measured in six studies and a significant relationship to carer burden was found in five of these. Other symptoms which were significantly associated with burden in more than 50% of the studies in which they were measured were irritability, psychotic symptoms, disruption to sleep and eating behaviour, frontal systems behaviour and anxiety. Symptoms which were less clearly associated with burden (i.e. in less than 50% of studies where measured) were apathy, depression and euphoria.

Studies using a global measure of BPSD

Of the studies which employed a global measure of BPSD, seven focussed on reporting the specific behaviours most associated with burden. Studies where participants were grouped into clusters according to symptoms found that the “psychotic/behavioural” cluster (Rocca et al. 2010), and the “irritability/agitation” and “psychotic symptom” clusters (Oh et al., 2015) were associated with higher levels of carer burden. Rocca et al. point out that within their “psychotic/behavioural” cluster, there was no differentiation between the impact of the individual BPSD, indicating that when a certain level of burden is reached, the presence of individual symptoms may not make a significant difference, whereas individual symptoms did have differential impact for less burdened carers.

Weinstein et al. (1991) found disoriented and dependent behaviour to be most closely associated with carer burden, while Victoroff et al. (1998) found agitation/aggression to be the only type of BPSD associated with burden. Victoroff et al. highlighted the importance of understanding the multifaceted nature of a symptom, such as agitation, rather than relying on a summary measure. In their study, physical aggression was found to be the most burdensome symptom for spousal caregivers, whereas non-

aggressive agitation, such as disrobing etc, was more closely linked to caregiver depression, confirming the value of employing a more specific measure to uncover complexities in the relationship between symptoms and caregiver outcomes. Onishi et al. (2005) found incontinence, disturbing conversation and care-recipient depression to be most associated with burden. This raises further issues for comparability, as they used a measure specifically designed for the study, whereas most measures do not include incontinence as a BPSD.

Allegri et al. (2006) found most symptoms on the NPI to be associated with burden, but highlighted the stronger association with positive symptoms, such as night-time behaviour disturbances, hallucinations and unusual motor behaviours, and the non-significant relationship of negative symptoms, such as apathy and depression, suggesting that negative symptoms are easier for caregivers to handle. The findings of Lou et al. (2015) directly contradicted these findings, in that apathy was the most closely associated symptom with carer burden. They propose an explanation for this, comparing their sample with that of Allegri et al. (2006). Ninety percent of the caregivers in the 2015 study cohabited with the care-recipient and all caregivers spent at least eight hours a day with the care-recipient. By contrast, in the 2006 study, only 40% were living with the care-recipient and the minimum time spent caring each week was 10 hours. Lou et al. propose that it is when caregivers spend most of their time with the care-recipient that negative symptoms such as apathy become more burdensome.

Of the remaining studies employing a global measure, three focussed on the difference between symptoms associated with burden and those associated with depression/distress. All three found that it was not the most severe or difficult to manage behaviours that were associated with burden, but those which are more likely to cause annoyance, frustration and embarrassment, whereas more severe behaviours tended to be associated with psychological morbidity in caregivers (Pruchno et al., 1989; Chappell & Penning, 1996; Donaldson et al., 1998). Two of the studies propose that caregivers' attributions of behaviour are central to this, in that more extreme dementia related behaviours, such as sexually inappropriate behaviour, incontinence or hallucinations are more likely to be perceived as outwith the care-recipient's control (Chappell & Penning, 1996; Pruchno et al, 1989), whereas

symptoms such as repetitive questions, apathy and aimlessness may result in more unhelpful attributions and an increase in burden.

Four studies considered the concept of the “wear and tear” hypothesis in the development of carer burden (i.e. burden will increase with length of time caring and coping with various BPSD), and whether this fitted with their results (Pruchno et al., 1989; Berger et al., 2005; Gaugler et al., 2010; Kamiya et al., 2014). All four studies found that changes in behaviour were more closely associated with burden than long periods of caregiving, and proposed that caregivers would benefit from support before and during periods of change, where adaptation to managing new symptoms is required.

Studies using specific measures of BPSD

Two studies measured agitation only, both finding it to be significantly correlated with burden (Yan & Kwok, 2010; Ozel-Kizil et al. 2014). Rymer et al. (2002) and Davis & Tremont (2007) both analysed the association between frontal systems behaviour and carer burden and found this to be significant. Both then went on to analyse the contribution of the three subscales of the FrSBe (executive function, disinhibition and apathy) in this relationship using multiple regression. The former found only disinhibition to be predictive, while the latter found both disinhibition and executive function to be involved. In line with Allegri et al, (2006) and contrary to Lou et al. (2015), neither study found apathy to be significantly associated with burden. Rymer et al. (2002) suggest that behaviours such as agitation, wandering and irritability may result from disinhibition, highlighting the relationship between disinhibition and burden as a priority for future research, as well as a focus for intervention.

The other studies into individual symptoms found significant associations with carer burden for theory of mind impairment (Guevara et al. 2015) and caregivers’ perception of nocturnal agitation (Kim et al. 2014). Riviere et al. (2002) did not find a significant correlation between aversive feeding behaviour and burden at baseline. However they did find that higher levels of carer burden at baseline were associated with later development of feeding behaviours, highlighting the potential bidirectional

influence of carer burden and BPSD of carer recipient, an important issue for consideration in all of the included studies.

Quality Assessment

Table 2 (below) shows the methodological quality ratings for each of the twenty-one papers, together with total scores, percentages and descriptive categories.

Background/Rationale

Almost all studies provided a good summary of background literature, theoretical rationale and addressed an appropriate and clear research question. Rationale for behaviours chosen and measurement of burden are discussed below.

Recruitment and confounding factors

Studies were rated on their reporting of diagnosis, definition of caregiver, and recruitment process, and this was well covered in most studies. As reported above, a range of diagnoses were included, with twelve studies focussing on one type of dementia only, potentially adding focus to the study, but also limiting generalisability of results. One study (Onishi et al. 2005) was unclear as to diagnosis used and therefore, particular care must be taken in generalising results from this.

A broad range of definitions of caregiver were used within the studies, with some specifying that the caregiver and care-recipient were co-residing, while others gave no inclusion criteria for the caregiver. However, issues such as hours spent caring and length of time as a carer were often addressed within the study, if not in the inclusion criteria. As these variables have been found to be associated with carer burden previously (Kim et al., 2011), studies are likely to be more robust when these factors are taken into account (Bedard et al., 2005; Davis & Tremont, 2007).

Studies were also rated on whether they accounted for demographic variables which have previously been found to be significant in their association with carer burden, e.g. gender and age of caregiver, and relationship to patient, and whether their inclusion was based on previous findings. Most studies took these variables into account, but only six included a rationale for this. In studies where an association was reported between these variables and carer burden, this was in line with previous research i.e. increased burden is associated with younger caregivers (Victoroff et al.,

Table 2: Quality Ratings

Study	Background / Rationale	Recruitment	Power calculation	Rationale and operationalisation of burden	Primary Outcome measures (behaviour and burden)	Confounding variables taken into account	Clusters of BPSD	Data analysis and results	Conclusions	Quality Score (/18) % and rating
Pruchno & Resch (1989)	2	2	0	0	0	1	0	2	2	9 50% - Fair
Weinstein et al. (1991)	2	2	0	1	1	1	1	2	2	12 67% - Fair
Chappell & Penning (1996)	2	2	0	1	2	2	1	2	2	14 78% - Good
Donaldson et al. (1998)	2	2	0	2	0	1	2	2	2	13 72% - Good
Victoroff et al. (1998)	2	2	0	1	2	2	2	2	2	15 83% -Good
Riviere et al. (2002)	2	2	0	0	2	1	2	2	1	12 67% -Fair
Rymer et al. (2002)	2	2	2	1	2	1	2	2	2	16 89% -Good
Berger et al. (2005)	2	2	0	1	2	1	1	2	2	13 72% -Good
Bedard et al. (2005)	2	2	0	2	2	2	2	2	2	16 89% - Good
Onishi et al. (2005)	0	0	0	0	1	1	2	1	0	5 28% -Weak
Allegri et al. (2006)	2	2	0	1	2	2	2	2	2	15 83% - Good

Study	Background / Rationale	Recruitment	Power calculation	Rationale and operationalisation of burden	Primary Outcome measures (behaviour and burden)	Confounding variables taken into account	Clusters of BPSD	Data analysis and results	Conclusions	Quality Score (/18) % and rating
Davis & Tremont (2007)	2	2	0	1	2	1	2	2	2	14 78% - Good
Rocca et al. (2010)	2	1	0	0	2	0	2	2	2	11 61% - Fair
Yan & Kwok (2010)	2	1	0	1	2	1	2	2	2	13 72% - Good
Gaugler et al. (2010)	2	2	0	1	2	2	2	2	2	15 83% - Good
Kamiya et al. (2014)	1	1	0	0	2	1	1	2	2	10 56% - Fair
Kim et al. (2014)	2	2	1	1	2	1	2	2	2	15 83% - Good
Ozel-Kizil et al. (2014)	2	0	0	2	2	1	2	2	2	13 72% - Good
Guevara et al. (2015)	2	0	0	0	0	0	2	2	1	7 39% - Weak
Oh et al. (2015)	1	2	0	2	2	0	2	2	2	13 72% - Good
Lou et al. (2015)	2	2	0	1	2	2	2	2	2	15 83% - Good

1998; Ozel-Kizil et al. 2014) and female caregivers (Donaldson et al., 1998; Bedard et al., 2005).

Rationale and Operationalisation of Burden

Burden is one of the most widely used terms in caregiver literature, but yet there is little agreement on its definition and conceptualisation. The studies were rated on the theoretical rationale provided for including burden as a measure, how it has been operationalised and whether subscales were used to address different dimensions of burden.

Despite the majority of studies focussing on carer burden as an outcome, nine of the studies did not include any theoretical background or rationale for including burden as an outcome. Four studies referred to the differentiation between burden and other constructs, such as depression, or to the difference between objective and subjective burden, in the introduction to the study, but with no further theoretical background. A more robust rationale and definition of burden was provided in a further four studies, but with no specific theoretical model discussed.

Only four studies included a theoretical model of burden as part of their rationale. Donaldson et al. (1998) derived their burden measure using Thompson and Doll's (1982) definition of subjective carer burden. Berger et al. (2005) describe the stress/health model of burden in dementia proposed by Schulz & Martire (2004) in their rationale. Yan & Kwok (2010) used McCubbin & Patterson's (1983) caregiver stress model to build their hypothesis of caregiver burden as an appraisal of the stressor (agitated behaviour), mediating between behaviour and caregiver abuse. Finally, Gaugler et al. (2010) used Pearlin's stress process model (Pearlin et al., 1990) to inform their study, particularly their selection of potentially influential covariates to be included.

It should be noted that, with the exception of Donaldson et al. (1998), none of these studies provided a clear link between the theoretical rationale provided and their choice of burden measure. Of the three studies which utilised subscales of burden measures, only Bedard et al. (2005) gave a rationale for their inclusion and elaborated on this in the discussion and conclusions.

Clusters of Symptoms Measured

In order to identify the BPSD most closely associated with burden, it is necessary either to measure individual symptoms or to group these in meaningful clusters. Studies were rated on the clusters of symptoms selected and whether these were well established in the literature.

Studies measuring a specific symptom or individual symptoms all provided an appropriate rationale and were rated as well covered. One study (Pruchno & Resch, 1989) described the development of a BPSD measure for the study, and the process of factor analysis for the three subscales. Chappell & Penning (1996) and Kamiya et al. (2010) used the Dementia Behaviour Disturbance Scale (DBD: Baumgarten et al., 1990) and described the factor analyses carried out to yield the subscales used in their studies. In each case, although the subscales had been derived using a robust method, the use of subscales which are not well established in the literature means that comparability of effects across studies is not meaningful.

The majority of studies (twelve) utilised established subscales, which had been well validated in previous research, enabling comparisons to be drawn across studies.

Quality of Measures Used

As described above, the majority of studies employed the ZBI as an outcome measure, which has been widely validated with this population. Other burden measures, such as the CBI (Novak et Guest, 1998) have also been found to have good psychometric properties. Most BPSD scales used have also been found to have acceptable reliability and validity within the population.

The majority of studies were rated as well covered for quality of measures, with a slight trend towards consistently higher ratings for later studies, possibly reflecting the expansion of this area of research.

Conclusions & Limitations

Most studies made clear links from their findings to their conclusions, with several studies using their results to address the conceptualisation of burden at this point (e.g. Chappell & Penning, 1996; Davis & Tremont, 2007) or to understand the processes involved (e.g. Kamiya et al., 2010; Guevara et al., 2015).

Limitations commonly identified were around the sample used e.g. lack of demographic information about the caregiver, under-representation of male caregivers, generalisability of findings to more burdened carers. Other limitations identified included use of a cross-sectional sample, lack of comparison/control group and reliance on self report measures.

Eighteen of the studies made recommendations for non-pharmological interventions to be developed and offered to caregivers. The majority suggested psycho-educational programmes providing information on dementia and problem focussed, behavioural management strategies. Six studies highlighted the need for interventions to focus on caregivers' perceptions and attributions regarding BPSD and three studies recommended psychosocial support, coping strategies or psychological therapy to be provided.

Discussion

BPSD and Burden

This review aimed to address the question of whether there are specific BPSD or clusters of symptoms that are more closely associated with carer burden. The studies reviewed overwhelmingly supported the established finding that BPSD are linked with carer burden (Ballard et al., 2000), with all studies finding a significant positive association with at least one symptom. Symptoms which were found to be significantly associated with burden in over 50% of the studies in which they were measured were aggression/agitation, frontal systems behaviour, disinhibition, disrupted eating and sleeping behaviour, unusual motor behaviour, anxiety and psychotic symptoms (hallucinations and delusions).

The conclusions that can be drawn from this, however, are limited. Firstly, the way in which the results of the various statistical analyses were reported make comparisons of effect size problematic. In addition, and more importantly, the behaviours described above are drawn from subscales of different measures, which vary in the items included and conceptualisation of the symptoms. A prime example is agitation, which, in some studies is measured in detail with the CMAI, in others, using the NPI, several varied items are included within the aggression/agitation scale, while in the BEHAVE-AD agitation is measured by one item. As highlighted by

Victoroff et al. (1998), who used both the CMAI and BEHAVE–AD to measure agitation, the global measures lack specificity, grouping verbal aggression, physical aggression and general lack of cooperation under one heading. However, global measures which have well established subscales, such as the NPI, used in four of the studies (Allegri et al., 2006; Rocca et al., 2010; Oh et al., 2015; Lou et al., 2015) allow for more meaningful comparison between studies, and have been recommended in the literature (Shah et al., 2005). The measures also vary in whether symptoms are scored on the basis of their presence, their frequency or their severity, each of which could have a different impact on carers and so should also be considered when selecting a measure and interpreting results from it.

Carer Burden

A further aim of this review was to explore the conceptualisation of burden employed in the literature. Despite the proliferation of research into carer burden within this population, the overwhelming majority of studies did not provide an adequate theoretical rationale for their selection of burden measure, or for the inclusion of burden as an outcome, an issue that has been highlighted previously (Bastawrous, 2013). Eighteen studies selected the ZBI as an outcome measure, which has the advantage of allowing comparison between studies, as it is the most widely used measure in the literature. However, it has been argued that burden is not a unidimensional construct (Springate & Tremont, 2014) and that the ZBI combines measures of both objective and subjective burden (Vitaliano et al., 1991). Therefore, relying on the total score of the ZBI is unlikely to capture the experience of the caregiver, and is too global in nature to inform researchers of appropriate foci for intervention.

Several studies partly addressed this issue, either by basing their rationale on a theoretical model of burden (Donaldson et al., 1998; Berger et al., 2005; Yan & Kwok, 2010; Gaugler et al. 2010) or by utilising subscales of the ZBI or CBI (Bedard et al., 2005; Ozel-Kizil et al., 2014; Oh et al., 2015). However, only Donaldson et al. (1998) and Bedard et al. (2005) provided a clear rationale running from their conceptualisation of burden to the selection of measure/subscales.

In order for research in this area to contribute further to the understanding of burden, it will be important to develop more specific, focussed measures of aspects of burden, or to study the factor structure of a measure such as the ZBI in order to produce a robust set of subscales which can be applied widely. This would allow the multifactorial nature of burden to be clarified and enable studies to more clearly identify the factors which impact on this.

Proposed Mechanisms

None of the studies explicitly aimed to measure potential mediating factors or mechanisms in the development of burden. However, theories were suggested from the findings of a number of the studies reviewed. Firstly, some studies identified that the type of symptoms which are linked with burden, rather than depression, are milder, but possibly more frequent and perceived as annoying or frustrating. It was proposed that caregivers may see these behaviours as being to some extent within the control of the care-recipient, and so the attributions they hold around this lead to increased carer burden (Pruchno & Rech, 1989; Chappell & Penning, 1996; Berger et al., 2004; Yan & Kwok, 2010). Secondly, four studies highlighted the importance of periods when a new symptom develops as the most burdensome for caregivers (Pruchno et al., 1989; Berger et al., 2005; Gaugler et al., 2010; Kamiya et al., 2014). This is important to note as it is often assumed that caregivers experience burnout over long periods of caring, but these studies identify a different process. This perhaps also draws out the further possibility of different facets of burden, one more linked with burnout and one with the immediate stress of coping with new demands. Finally, Lou et al. (2015) proposed that caregivers who spend more time with the care-recipient are more likely to find negative symptoms, such as apathy, stressful. For someone who spends all day with the care-recipient, it may become more distressing to experience the loss of the active person they previously knew, while reduced motivation and initiation may mean that extra support with activities of daily living are required. This is another area which may benefit from further research.

Implications for practice

BPSD are consistently linked with carer burden, and so it will be important for practitioners to be aware of this potential where such symptoms are evident or are

likely to develop. As burden and depression have been found to be separate constructs, impacted by different factors, it will be important to ensure that caregivers' assessments include some type of burden measure in addition to any general mental health assessment. Burden has been found to be complex and multifactorial, so burden assessments should be designed to pick up some of the complexities involved, and tailored interventions developed once the nature of the burden is established.

Group or individual interventions may also be effective, particularly if they involve psychoeducation around BPSD and the reasons behind these. This type of intervention may help alter carers' attributions, thereby changing their responses to difficult behaviour. Preparing carers for changes that may occur in the person for whom they are caring, and providing strategies to manage these may also help to reduce the burden experienced by caregivers when new symptoms emerge (Gaugler et al., 2010).

It should also be noted that the term "Behavioural and Psychological Symptoms of Dementia (BPSD)" was introduced by the International Psychogeriatric Association in 1999 to replace the term "behavioural disturbances" (Finkel & Burns, 1999), and is used in this review due to the widespread international consensus on its use within research. However, within clinical settings, BPSD is often considered to draw focus away from environmental, interpersonal and organisational factors, with the implication that treatment should be targeted at the behaviour. The term "stress and distress" is now more commonly used in clinical practice to reflect the complex interplay between internal and external factors, and behavioural changes as an expression of unmet needs (James, 2011). The more widespread use of this latter approach may enable caregivers to develop more insight into needs which may be expressed through behaviour, altering their attributions and empowering them to understand and respond to changes in behaviour as they occur.

Limitations of review

The heterogeneity across studies, particularly in terms of BPSD measures and conceptualisation of symptoms was a major limitation for this review. The principal research question was whether any symptom or cluster of symptoms was most

closely associated with carer burden and it was not possible to draw comparisons between studies in order to address this. As recommended by Shah et al. (2005) the development of a global tool to be used across studies would allow a clearer definition of symptoms and more meaningful comparisons to be drawn. A further source of heterogeneity is in the definition of the term, “carer” or “caregiver” across studies. Studies ranged widely in the number of hours a caregiver had to spend in the caregiving role each week, with some studies omitting to provide this information at all. As highlighted by Lou et al. (2015), it is highly likely that there would be a significant difference between a caregiver who spends 10 hours a week with the care-recipient and one who lives with them, in terms of the impact of BPSD. Again, caregiving role must be more clearly defined in future studies if comparisons are to be possible.

Further limitations of this review are similar to those of the individual studies, in that the overall sample was heavily weighted towards female caregivers and is likely to be biased in terms of caregivers who are able to take the time to participate in research. An inherent difficulty in research into carer burden is that those who are most burdened are unlikely to have time or energy to participate and so studies are biased towards those who are experiencing only mild to moderate levels of burden. Increased levels of burden are also likely to be a barrier to caregivers accessing support services, and so researchers should be aware that there may be a proportion of caregivers whose experience is missed. This may also be true in part for male caregivers who are under-represented in the literature and have been found to be less likely to access services (Greenwood & Smith, 2015).

By only including studies using the concept of “burden” and limiting search terms to particular BPSD, studies which could add to the understanding of the effect of BPSD on caregiver outcomes may have been omitted from this review. The focus on burden, however, did allow the conceptualisation of this within the existing literature to be explored more fully. The inclusion of grey literature, e.g. unpublished theses and dissertations, was outwith the scope of this review. However, this introduces the possibility of publication bias in the studies included and may have resulted in significant findings being overlooked.

Finally, as there were no specific tools already developed suitable to assess the quality of these studies, the quality rating tool was developed specifically for this study, and may therefore limit the generalisability of the findings. However, inter-rater reliability was good, and so indicates the tool was sufficiently robust.

Future research

As this review was concerned with the association between BPSD and burden, no conclusions can be drawn regarding the direction of the effect. This was highlighted by Riviere et al.(2002), who found that higher rates of burden at baseline were associated with aversive feeding behaviour one year later, suggesting a bidirectional effect between BPSD and burden. Future longitudinal studies might be helpful in exploring the nature of this relationship. As discussed, studies exploring the dimensions of carer burden may also be helpful in providing measures that more accurately capture caregivers' experience.

It is now well established that BPSD are associated with carer burden, and it may that, rather than focussing on which individual symptoms are most burdensome, research could usefully focus on the mechanisms by which these behaviours affect caregivers e.g. attributional style, coping strategies, behaviour management. It may be that these types of study can be more helpful in informing caregiver intervention.

Conclusion

There is a wealth of research into factors impacting on carer burden in dementia, and BPSD have consistently been found to be involved. All symptoms have been found to be correlated with burden and it is not clear whether any are more closely associated than others. Despite the growing body of literature around carer burden, there still remains very little consensus regarding its definition or conceptualisation, and few studies include a theoretical basis for its inclusion. Future research could helpfully focus on clarifying the dimensions of carer burden and the mechanisms by which BPSD impact negatively on caregivers. This more focussed approach would allow more targeted interventions to be developed.

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Journal Article 1

An exploration of carer burden and positive gain in dementia: the role of executive functioning deficits, management strategies and experiential avoidance

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Abstract

Objectives

Behavioural and psychological symptoms of dementia (BPSD) have been well established as factors involved in the development of carer burden. However, it is not clear which symptoms are most burdensome for caregivers and which caregiver factors may be involved. This study explored symptoms associated with executive functioning deficits and their impact on three dimensions of carer burden and positive gain. It also aimed to discover whether behaviour management strategies employed by caregivers, and their level of experiential avoidance, had an independent impact on these factors.

Methods

One hundred and ten dementia caregivers completed the following self-report measures as part of a cross-sectional design: the Dysexecutive Questionnaire (DEX), Zarit Burden Interview (ZBI), Positive Aspects of Caregiving Questionnaire (PAC), Dementia Management Strategies Scale (DMSS) and Experiential Avoidance in Caregiving Questionnaire (EACQ).

Results

Executive functioning deficits (DEX) were found to account for most variance in burden, with DEX subscales impacting differentially on the three dimensions of burden and positive gain. The use of negative management strategies was associated with higher levels of burden, as was Active Avoidant Behaviour (a subscale of the EACQ), while positive management strategies were associated with positive gain.

Conclusions

In line with previous findings, symptoms associated with executive functioning deficits were the most significant factor in the development of carer burden. The findings relating to behaviour management strategies and experiential avoidance suggest that these could be potential mediating mechanisms in this relationship. Further research is required to explore this in detail, and to consider implications for targeted carer interventions.

Introduction

Background

As average life expectancy increases, a growing number of people are at risk of developing some form of dementia and requiring varying levels of care. The use of professional caregivers and residential placements puts significant strain on services and, for the person with dementia and their family, it can be distressing when care can no longer be provided at home. It is therefore increasingly important to ensure that family carers are provided with the necessary support to continue caring for their relative for as long as possible, a priority reflected in current UK government policy (NICE & SCIE, 2006; Scottish Government, 2013; SIGN, 2006).

Carer Burden

Carer burden is widely reported as one of the main reasons caregivers feel they can no longer support their relatives at home. It has been conceptualised in numerous studies, and is generally considered to involve a combination of objective and subjective elements (Brodaty *et al.*, 2005; Wang *et al.*, 2014). Objective burden is most often conceptualised as including factors such as level of input from services, financial strain, social support and patient symptomatology, and subjective burden as consisting of caregivers' emotional and cognitive reactions to the situation (Oyebode, 2003). Despite this distinction being well established in the literature and studies identifying different correlates associated with each (e.g. Montgomery *et al.*, 1985a), most commonly used burden measures fail to distinguish between objective and subjective burden (Vitaliano *et al.*, 1991)

In addition, there has been wide criticism of the lack of theoretical rationale within the literature for the inclusion of burden as an outcome measure (Bastawrous, 2013), as well as its conceptualisation as a unidimensional construct (e.g. Lau *et al.*, 2015). Studies such as Berger *et al.* (2005) and Lou *et al.* (2015) found care recipient behaviours impacted differently on carer burden and depression, while other studies have found unique predictors for various dimensions of burden. For example, Springate and Tremont (2014) found that the age of the caregiver (younger caregivers) was a predictor of "impact on caregiver life" and "guilt", while

behavioural problems only predicted “frustration/embarrassment”. The importance of measuring multiple components of burden, supported by theoretical background, in order to capture the complexity of caregiver experience, has therefore been highlighted (Lau *et al.*, 2015, Roach, 2013).

The concept of burden remains ill defined and at risk of overuse within the existing literature. However, the potential role of burden in the development of psychological morbidity, such as depression, deems it a vital area to explore in order to inform the development of early interventions for this high risk population. Therefore, endeavouring to conceptualise the components of burden and identify potential mechanisms in its development will be crucial steps in this process.

Executive Dysfunction and Behaviour Problems

Personality and behaviour changes associated with dementia can form a significant part of the objective burden experienced by caregivers (Brodaty *et al.*, 2005), while also having a major impact on levels of subjective burden and ability to manage care at home (Gaugler *et al.*, 2009; Ornstein & Gaugler, 2012). Many of these behaviours may be associated with deficits in executive function, which have been proposed as a core feature of all types of dementia (Royall *et al.*, 2011; Voss & Bullock, 2004).

A study by Campbell and McAfee (2013) using the Dysexecutive Questionnaire (DEX: Burgess *et al.*, 1996) identified planning problems, lack of insight, perseveration and distractibility, as the dysexecutive problems most frequently experienced by caregivers of patients with Alzheimer’s Disease. However, as no measure of caregiver distress was included within this study, it cannot be assumed that the pattern of difficulties identified is the most burdensome for caregivers. Davis & Tremont (2007) found links between caregiver reported executive functioning difficulties and levels of burden, even after controlling for dementia severity and caregiver depression. This finding was supported in a study by Rosas-Carrasco *et al.* (2014) who found that overall executive dysfunction, as reported by caregivers, was more closely linked with carer burden than any caregiver variables. Impairment in executive function can result in behaviours such as lack of inhibition, repetitive questioning (perseveration), socially inappropriate behaviour and aggression, all of

which have also been individually linked with carer burden/stress (Lim *et al.*, 1999; Reis *et al.*, 1994; Rymer *et al.*, 2002).

Although many studies have identified links between overall behaviour or specific behaviours and carer burden, it is not yet clear which problems are most prevalent or problematic for dementia caregivers, and therefore those which might provide an appropriate focus for caregiver intervention. Ornstein and Gaugler (2012) attempted to identify patterns of behavioural difficulties most commonly associated with carer burden through a review of relevant studies, but found no consistent clusters of symptoms associated with this. An issue raised in this study and within the wider literature as a barrier to clarifying this relationship is the heterogeneity of measures used to categorise behavioural and psychological symptoms of dementia (BPSD) and therefore the difficulty in drawing comparisons across studies.

The first aim of this study will be to explore the executive functioning difficulties most frequently reported by caregivers and their impact on carer burden. It is hypothesised that overall higher levels of executive functioning difficulties will be significantly associated with higher levels of carer burden and lower levels of positive gain. In addition, the study will explore the relationship between different types of executive difficulties and dimensions of carer burden.

Potential causal mechanisms

Caregivers vary considerably in their level of subjective burden, despite reporting similar objective elements, and many studies have proposed mediating and moderating variables to account for this. Papastavrou *et al.* (2011) found that use of positive coping strategies, such as problem solving and reappraisal, was correlated with lower levels of carer burden. Gallagher *et al.* (2011) found that self-efficacy for management of behavioural symptoms of dementia mediated between neuropsychiatric symptoms and burden for caregivers of patients with moderate to severe dementia, while Bruvik *et al.* (2013) found that locus of control was the most important caregiver variable in predicting burden. These findings suggest that when caregivers feel they have some control of the situation, are able to utilize a problem

solving, analytic approach to the difficulties they face and feel confident in managing behavioural symptoms, they experience lower levels of burden.

Behaviour management

Only a small number of studies have measured the impact of the type of behaviour management strategies used by caregivers. Strategies such as criticism, behavioural disengagement and active management have been linked with greater caregiver burden (Hinrichsen & Niederehe, 1994; Lim *et al.*, 2011) while ‘non-adapting’ caregiver behaviour (e.g. use of criticism) has been found to be predictive of further behavioural problems in the care-recipient (de Vugt *et al.*, 2004). Conversely, Lim *et al.*, (2011) found that the use of encouragement in caregivers was correlated with caregivers’ reported positive gain (i.e. perceived benefits experienced through caregiving).

Experiential Avoidance

Until relatively recently, research around caregivers’ cognition has focussed on dysfunctional thoughts, linking these with negative outcomes, and thus interventions have focussed on modifying these (e.g. Gallagher-Thompson & Coon, 2007; Marquez-Gonzalez *et al.*, 2007). Research within the Acceptance and Commitment Therapy (ACT) approach has shown that attempts to avoid or suppress difficult or negative thoughts can conversely increase their occurrence and can reduce individuals’ capacity for living a meaningful life adhering to their values (Flaxman *et al.*, 2011). This process is known as experiential avoidance and has been found to be linked with depression in various populations (Ruiz, 2010), and specifically in dementia caregivers (Spira *et al.* (2007). At the time of writing, there are no known studies measuring both experiential avoidance and carer burden.

In addition to exploring the effects of executive functioning deficits on carer burden and positive gain, it is hypothesised that the behaviour management strategies used by caregivers and caregivers’ level of experiential avoidance will have a significant effect on carer burden and positive gain, over and above the contribution of age of caregiver and care-recipient, gender, relationship and behavioural problems as measured by the DEX.

Methodology

Participants

The current study was adopted by the Scottish Dementia Clinical Research Network, who provided access to a database of caregivers throughout Scotland who had expressed an interest in participating in research (adoption letter included in Appendix 3). All five hundred and eleven eligible caregivers on the database were approached. An initial participant information sheet was sent out, together with a form on which caregivers could express their interest. Those who returned the form, received a further information sheet, questionnaire pack and consent form. Eighty eight completed sets of data were received through this process. A further twenty two participants, who were recruited through voluntary carer agencies and NHS clinicians to participate in an intervention study, were also approached to take part in the current study and completed the measures prior to the start of the intervention. Ethical approval was received through South East of Scotland NHS Research Ethics Committee, NHS Lothian Research and Development and the University of Edinburgh, School of Health in Social Science (see Appendix 4 & 5).

Paid carers were excluded from the study, and caregivers were only included if the person for whom they were caring was residing at home. All forms of dementia diagnosis were included.

Design & Measures

A cross-sectional quantitative design was used. Participants completed five self-report measures:

The Dysexecutive Questionnaire (DEX): The DEX questionnaire (Burgess *et al.*, 1996) is a 20 item self report measure, which forms part of the Behavioural Assessment of the Dysexecutive Syndrome (BADS; Wilson *et al.*, 1996). It has been used in various populations, including studies with dementia patients (Campbell & McAfee, 2013; Rosas-Carrasco *et al.*, 2014). The questionnaire consists of a self rated version to be completed by the patient, and an independent rater version to be

completed by someone who knows the person well. The independent rater version was used in this study.

Various studies have performed factor analyses on the DEX (self and independent rater versions), revealing multiple components. This study uses the five subscales proposed by Burgess *et al.*, (1998) which drew on data from a moderate sample size of patients of mixed aetiology, including dementia. These subscales are: inhibition, intentionality, executive memory, positive affect and negative affect (See Appendix 10 for details of subscales).

The Zarit Burden Interview (ZBI): The 22 item ZBI (Zarit *et al.*, 1985) was originally developed for use with dementia caregivers and is still the most widely used measure both for screening purposes and as an outcome measure. It has been shown to have good validity and reliability (Cronbach's $\alpha = 0.92$; Hebert *et al.*, 2000), as well as internal consistency (e.g. Wang *et al.*, 2008).

Despite the concerns previously described regarding the utility of any measure of carer burden, it was decided that, due to its widespread prior use and therefore the possibility of comparing outcomes across studies, the ZBI would be used for this study. However, as recommended in recent literature on the concept of burden, the potential causal mechanisms are clearly operationalized, and subscales of the ZBI will be analysed. The three dimensions revealed in a factor analysis carried out by Springate & Tremont (2014) were considered most appropriate for this study, as the sample of caregivers is similar, and the dimensions potentially relevant to the causal mechanisms explored. The dimensions are: impact of caring on caregivers' lives, guilt and frustration/embarrassment.

The Positive Aspects of Caregiving Scale (PAC): The PAC (Tarlow *et al.*, 2004) was developed with a sample of 1229 dementia carers in order to assess perceived benefits of caregiving, and has been found to have good validity and reliability (Cronbach's $\alpha = 0.89$; Hilgeman *et al.*, 2007; Tarlow *et al.*, 2004). It is a nine-item self-report measure consisting of positive statements about caregiving rated on a 5 point Likert scale. In previous studies it has been found to be related to self

efficacy (Semiatin & O'Connor, 2012) but also to represent a unique construct, distinct from related constructs such as mental wellbeing (Hilgeman *et al.*, 2007).

The Dementia Management Strategies Scale (DMSS): The DMSS was developed to measure specific ways in which family-members manage dementia related problems, and was found to have adequate reliability and validity in a sample of family caregivers in the US (Hinrichsen & Niederehe, 1994). The scale consists of 28 self report items, and factor analysis initially indicated three subscales: criticism, encouragement and active management. Although these subscales have good internal consistency, on assessing the items qualitatively, several do not seem to fit with the definitions of the constructs within current UK culture. A similar argument was also raised with regard to Singapore culture in a study by Tan *et al.* (2013), resulting in the proposal of two subscales: positive and negative behaviours, and the removal of 8 items from the scale. It was decided that subscales from the Tan *et al.*, (2013) study would be most appropriate for use in this study.

The Experiential Avoidance in Caregiving Questionnaire (EACQ): The EACQ (Losada *et al.*, 2014) is a 15 item self report measure, based on the widely used and well established AAQ (Hayes *et al.*, 2004). It has been found to have acceptable psychometric properties (reliability for the total scale is reported as Cronbach's $\alpha = .70$; Losada *et al.*, 2014) and yields three subscales: Active Avoidant Behaviours (AAB: $\alpha = .63$); Intolerance of Negative Thoughts and Emotions Towards the Relative (INT: $\alpha = .71$) and Apprehension Concerning Negative Internal Experiences Related to Caregiving (APP: $\alpha = .60$).

Statistical Analysis

All analyses were carried out on SPSS version 21. Little's MCAR test was carried out on missing data and did not reach significance ($p = .281$). Therefore, missing values could be assumed to be missing completely at random. The Expectation-Maximisation algorithm was then used to produce maximum likelihood estimates for the missing values (Graham, 2009).

Descriptive statistics are shown in Table 1. Pearson correlation coefficients were calculated to explore the relationships between predictor variables and the dependent

variables of burden (ZBI) and positive gain (PAC). A series of hierarchical multiple regression analyses were then carried out, with the ZBI total score, each of the ZBI subscales and the PAC total score as dependent variables. All demographic data was put into the model at step 1 and DEX subscales were added at step 2 to assess whether dysexecutive symptoms were predictive of burden and positive gain after accounting for age, gender and relationship. DMSS was added at step 3 and EACQ at step 4. As two of the subscales of the EACQ (INT and APP) had not performed as expected in the correlational analysis, creating some uncertainty around the validity of the measure, it was decided to enter the DMSS and EACQ independently to ensure that this did not affect the DMSS analyses.

Bias-corrected bootstrapping was used in all correlation and regression analyses (Hayes, 2013).

Results

Demographic data and descriptive statistics are shown in Table 1. In this sample, 75 caregivers were female and 35 male, 89 were spouses, 20 were adult children and 1 was a sibling. The mean age was 69.5 for carers and 77.3 for care-recipients.

Table 1: Description of sample and mean total scores for predictor and dependent variables (N=110)

	N	Mean	SD	Range
Gender:				
Male	35			
Female	75			
Relationship:				
Spouse	89			
Child	20			
Other (sister)	1			
Age of carer		69.5	11.92	36-98
Age of recipient		77.26	9.14	54-94
DEX total		43.62	13.82	11-75
ZBI total		41.05	14.58	12-69
PAC total		18.9	7.64	0-36
EACQ total		31.44	6.70	16-48
DMSS+ve		30.8	6.82	10-47
DMSS-ve		7.83	4.84	0-24

Frequencies of dysexecutive behaviours

Total individual item and subscale scores for the DEX were calculated, in order to gain a sense of which dysexecutive behaviours are most commonly reported. For individual items, the total possible score from 110 participants is 440. The highest scoring items for frequency of occurrence were planning problems (380), difficulty with decision making (366), temporal sequencing difficulties (325), abstract thinking problems (323) and distractibility (317). The lowest scoring item was aggression (132) (see Table 2 below).

Scores were calculated for each subscale as a percentage of the total possible score for that scale to assess which subtype of dysexecutive behaviour is most frequently reported. Intentionality was the most frequently reported with a percentage score of 69.77%, while Positive Affect, which includes both euphoria and aggression, had the lowest percentage score of 35.08% (see Table 3 below).

Table 2: Total score for each individual item on DEX

Individual DEX item	Total score /440
Planning problems	380
Poor decision-making ability	366
Temporal sequencing deficits	325
Abstract thinking problems	323
Distractibility	317
Lack of insight and social awareness	295
Apathy and lack of drive	282
No concern for social rules	277
Perseveration	256
Impulsivity	254
Confabulation	205
Lack of concern	196
Shallowing of affective responses	195
Variable motivation	179
Knowing-doing dissociation	177
Restlessness-hyperkinesis	172
Inability to inhibit responses	170
Euphoria	152
Disinhibition	146
Aggression	132

Table 3: Frequency of each factor of DEX within the sample

Factors of dysexecutive syndrome as measured by DEX	Total score as percentage of total possible score
Intentionality	69.77%
Executive Memory	59.55%
Negative Affect	54.20%
Inhibition	49.94%
Positive Affect	35.08%

Table 4: Bivariate correlations between all independent and dependent variables

	ZBI (impact on caregiver life)	ZBI (guilt)	ZBI (frustration/ embarrassment)	ZBI (total score)	PAC (total score)
Carer characteristics:					
Gender	.20* [.011,.372]	-.04 [-.219,.141]	.17 [-.016,.339]	.15 [-.031,.338]	-.16 [-.334,.016]
Relationship to recipient	-.24* [-.403,-.061]	-.23* [-.405,-.035]	-.07 [-.247,.093]	-.26* [-.405,-.082]	.22* [.022,.405]
Age	-.35** [-.500,-.179]	-.26** [-.416,-.097]	-.16 [-.345,.019]	-.36** [-.515,-.191]	.14 [-.081,.370]
Care recipient characteristics:					
Age	-.14 [-.338,.059]	-.15 [-.349,.066]	.07 [-.117,.266]	-.13 [-.321,.066]	-.05 [-.208,.118]
DEX:					
Inhibition	.59** [.435,.715]	.37** [.201,.528]	.42** [.277,.551]	.61** [.476,.720]	-.14 [-.312,.034]
Intentionality	.50** [.361,.627]	.40** [.252,.522]	.37** [.208,.515]	.56** [.428,.675]	-.22* [-.387,-.070]
Executive Memory	.47** [.323,.602]	.32** [.153,.466]	.46** [.299,.603]	.49** [.356,.616]	-.21* [-.360,-.048]
Positive Affect	.36** [.150,.536]	.15 [-.050,.345]	.39** [.223,.554]	.37** [.171,.538]	-.11 [-.301,.085]
Negative Affect	.39** [.216,.549]	.38** [.199,.513]	.28** [.098,.459]	.46** [.307,.610]	-.19* [-.362,.007]
Total DEX	.62** [.453,.732]	.42** [.267,.555]	.50** [.373,.624]	.66** [.527,.761]	-.21* [-.386,-.050]
DMSS:					
Positive strategies	.001 [-.192,.186]	-.08 [-.277,.099]	-.07 [-.274,.130]	-.03 [-.243,.189]	.23* [.031,.430]
Negative strategies	.50** [.312,.647]	.42** [.211,.609]	.40** [.189,.595]	.52** [.370,.650]	-.17 [-.362,.014]
EACQ:					
Active Avoidant Behaviours	.21* [.012,.390]	.25** [.088,.420]	.20** [.043,.350]	.24* [.054,.410]	-.03 [-.206,.152]
Intolerance of negative thoughts/emotions towards relative	-.37** [-.541,-.189]	-.14 [-.315,.047]	-.27** [-.445,-.089]	-.34** [-.508,-.151]	.21* [.021,.375]
Apprehension Concerning Negative Internal Experiences Related to caregiving	-.24* [-.433,-.039]	-.10 [-.300,.091]	-.15 [-.349,.055]	-.22* [-.425,-.022]	.17 [-.042,.374]
EACQ Total	-.16 [-.367,.039]	.03 [-.155,.202]	-.09 [-.273,.103]	-.12 [-.326,.073]	.15 [-.05,.34]

*p<.05, **p<.01 (2 tailed), BCa bootstrap 95% CIs reported in brackets, based on 1000 bootstrap samples.

Correlational Analyses

Bivariate correlation coefficients were calculated to explore the relationships between all independent variables, and ZBI and PAC. The results are presented in Table 4. As predicted by the hypothesis, higher scores on all subscales on the DEX were associated with higher scores on all dimensions of burden (ZBI). In addition, higher reported levels of dysexecutive symptoms on the DEX were associated with lower scores for perceived positive aspects of caregiving (PAC), though this relationship was not significant for all subscales of the DEX. More frequent use of negative behaviour management strategies was also associated with higher levels of burden, while increased use of positive strategies correlated with positive gain. Finally, greater use of active avoidant behaviours, as recorded on the EACQ, was associated with higher levels of burden. However, higher levels of cognitive avoidance strategies, i.e. ‘intolerance of negative thoughts toward relative’ and ‘apprehension concerning negative internal caregiving related experiences’ were associated with lower levels of some dimensions of burden.

Regression Analyses

Results of the hierarchical regression analyses are presented in Table 5. In line with the primary hypothesis, dysexecutive symptoms accounted for a significant share of the variance of all dimensions of burden, after accounting for age of caregiver and care-recipient, gender of caregiver and relationship to care-recipient (between 21% and 36% of variance for the 4 dimensions of burden). In addition, the secondary hypothesis was partly supported, in that the type of dementia management strategies used accounted for a significant share of explained variance of burden, over and above age, gender, relationship and dysexecutive symptoms. However, experiential avoidance (added at step 4) only accounted for a significant share of the variance in total burden and impact on caregiver life. Results relating to certain subscales of the EACQ are potentially problematic and should be interpreted with caution as discussed below. When a regression was run with PAC as the dependent variable, only the addition of dementia management strategies was shown to be a significant predictor of this outcome ($\Delta R^2 = .09$, $\Delta F(2,98) = 5.40$, $p = .006$).

Table 5: 95%BCa confidence intervals in brackets. Confidence Intervals and standard errors based on 1000 bootstrap samples

		ZBI: Impact on Caregiver Life				ZBI: Guilt				ZBI: Frustration/ Embarrassment			
		b	SE B	β	p	b	SE B	β	p	b	SE B	β	p
Step1	Carer gender	0.28 (-2.49,3.47)	1.56	.02	.88	-1.30 (-2.69,0.14)	0.74	-.18	.08	-0.36 (-1.71,1.09)	0.67	-.05	.58
	Carer age	-.01 (-0.28,0.23)	0.12	-.01	.96	-0.00002 (-0.11,0.11)	0.06	.00	1.0	-0.14 (-0.24,-0.05)	0.05	-.53	.002
	Relationship to c-r	-2.47 (-8.50,4.73)	2.96	-.11	.36	-2.48 (-4.95,-0.18)	1.13	-.29	.02	3.82 (1.52,6.20)	1.21	.47	.002
	Care Recipient age	0.03 (-0.20,0.17)	0.10	.03	.74	-0.04 (-0.13,0.04)	-.003	-.11	.35	0.16 (0.08,0.26)	0.04	.47	.001
Step2	DEX Inhibition	0.37 (0.05,0.67)	0.17	.25	.03	-0.001 (-0.18,0.16)	0.09	-.002	.99	0.09 (-0.05,0.22)	0.08	.16	.26
	DEX Intentionality	0.19 (-0.29,0.73)	0.24	.08	.44	0.15 (-0.03,0.34)	0.10	.17	.12	-0.03 (-0.24,0.24)	0.11	-.03	.81
	DEX Executive Memory	0.52 (0.02,1.07)	0.27	.19	.06	0.12 (-0.13,0.36)	0.13	.11	.39	0.22 (0.01,0.40)	0.12	.22	.06
	DEX Positive Affect	-0.28 (-0.91,0.42)	0.32	-.09	.39	-0.20 (-0.48,0.09)	0.14	-.17	.15	0.13 (-0.11,0.38)	0.12	.12	.29
	DEX Negative Affect	0.51 (-0.13,1.19)	0.33	.12	.12	0.37 (0.05,0.64)	0.16	.22	.03	0.15 (-0.18,0.52)	0.17	.09	.38
Step3	DMSS positive	-0.10 (-0.26,0.06)	0.09	-.08	.25	-0.05 (-0.12,0.03)	0.04	-.10	.25	-0.07 (-0.14,0.01)	0.04	-.14	.08
	DMSS negative	0.43 (0.13,0.67)	0.14	.24	.01	0.18 (0.07,0.31)	0.07	.27	.01	0.10 (-0.05,0.28)	0.07	.15	.18
Step4	EACQ AAB	0.33 (-0.07,0.70)	0.21	.13	.11	0.20 (0.02,0.37)	0.09	.20	.04	0.13 (-0.05,0.29)	0.09	.14	.13
	EACQ - INT	-0.50 (-1.00,-.01)	0.26	-.17	.05	-0.05 (-0.26,0.15)	0.12	-.04	.69	-0.14 (-0.39,0.14)	0.12	-.13	.23
	EACQ - APP	-0.34 (-0.74,0.07)	0.21	-.12	.12	-0.10 (-0.31,0.10)	0.10	-.09	.28	-0.10 (-0.29,0.10)	0.10	-.09	.35
		R ² =.13 for step 1 (p=.01); ΔR^2 =.31 for step 2 (p<.001); ΔR^2 =.09 for step 3 (p<.001); ΔR^2 =.04 for step 4 (p=.05)				R ² =.10 for step 1 (p=.03) ΔR^2 =.21 for step 2 (p<.001) ΔR^2 =.09 for step 3 (p=.001) ΔR^2 =.03 for step 4 (p=.14)				R ² =.11 for step 1 (p=.02) ΔR^2 =.25 for step 2 (p<.001) ΔR^2 =.06 for step 3 (p=.006) ΔR^2 =.03 for step 4 (p=.22)			

Table 5 (cont): 95%BCa confidence intervals in brackets. Confidence Intervals and standard errors based on 1000 bootstrap samples

		ZBI: Total score				Positive Aspects of Caregiving			
		B	SE B	β	p	b	SE B	β	p
Step1	Carer gender	-2.16 (-7.03,3.17)	2.51	-.07	.39	-1.31 (-4.54,2.21)	1.66	-.08	.43
	Carer age	-0.16 (-0.55,0.20)	0.19	-.13	.36	-0.19 (-0.48,0.08)	0.16	-.29	.24
	Relationship to c-r	-2.57 (-10.84,7.25)	4.46	-.07	.54	7.93 (0.54,17.30)	4.12	-.41	.04
	Care Recipient age	0.09 (-0.20,0.39)	0.15	.06	.56	0.11 (-0.14,0.41)	0.14	.13	.45
Step2	DEX Inhibition	0.51 (-0.07,1.07)	0.28	.20	.07	0.26 (-0.13,0.62)	0.20	.19	.20
	DEX Intentionality	0.55 (-0.20,1.41)	0.40	.14	.18	-0.52 (-1.11,0.03)	0.30	-.26	.09
	DEX Executive Memory	0.74 (-0.12,1.52)	0.43	.16	.08	-0.06 (-0.71,0.66)	0.31	-.02	.86
	DEX Positive Affect	-0.40 (-1.31,0.70)	0.50	-.08	.45	-0.19 (-0.87,0.50)	0.34	-.07	.58
	DEX Negative Affect	1.43 (0.58,2.39)	0.47	.20	.003	-0.44 (-1.30,0.39)	0.40	-.12	.25
Step3	DMSS positive	-0.24 (-0.51,0.06)	0.15	-.11	.11	0.30 (0.06,0.50)	0.11	.26	.01
	DMSS negative	0.74 (0.38,1.11)	0.20	.25	.001	-0.13 (-0.47,0.29)	0.18	-.08	.46
Step4	EACQ AAB	0.69 (0.02,1.35)	0.33	.16	.04	-0.01 (-0.51,0.37)	0.24	-.003	.98
	EACQ - INT	-0.69 (-1.38,0.09)	0.38	-.14	.06	0.31 (-0.28,0.88)	0.29	.12	.27
	EACQ - APP	-0.64 (-1.47, 0.15)	0.37	-.13	.08	0.38 (-0.25,0.97)	0.30	.14	.20
		R ² = .13 for step 1 (p=.005); Δ R ² = .36 for step 2 (p<.001); Δ R ² = .10 for step 3 (p<.001); Δ R ² = .04 for step 4 (p=.02)				R ² = .06 for step 1 (p=.16) Δ R ² = .06 for step 2 (p=.21) Δ R ² = .09 for step 3 (p=.006) Δ R ² = .03 for step 4 (p=.25)			

Examination of individual predictors indicated the following (see Table 5 for figures; as bias corrected bootstrapping was used for the analyses, predictors are considered statistically significant if the 95% confidence intervals do not cross zero):

- DEX inhibition subscale, DEX executive memory subscale, and DMSS negative were significantly predictive of ZBI impact on caregiver life.
- Relationship to care-recipient (being an adult child rather than a spouse), DEX negative affect, DMSS negative, and EACQ AAB were significantly predictive of ZBI guilt.
- Age of caregiver (younger carer), age of care-recipient (older), relationship to care-recipient (being a spouse) and DEX executive memory were all significantly predictive of ZBI frustration/ embarrassment.
- DEX negative affect, DMSS negative and EACQ AAB were significantly predictive of ZBI total score.
- Relationship to care-recipient (spouse rather than child) and DMSS positive, were significantly predictive of perceived Positive Aspects of Caregiving.
- EACQ INT was significantly predictive of ZBI impact on caregiver life in a negative direction.

Discussion

Frequency of dysexecutive behaviours

The most frequently reported executive functioning difficulties reported in this study were broadly in line with the findings of Campbell & McAfee (2013), who also found planning and distractibility to be among the highest scoring items on the DEX. The high frequencies reported for planning, decision making and sequencing may also reflect the prevalence of cognitive difficulties reported by carers in other studies. Fauth & Gibbons (2014) found that memory problems were the most frequent but least distressing symptom reported by caregivers, while disruptive behaviour was least frequent and most distressing, indicating that the most common or frequent symptoms of dementia do not necessarily result in high levels of burden for caregivers. In this study, aggression, conceptualised in the DEX as “loses his/her

temper at the slightest thing”, was the least frequently reported behaviour, which, though apparently similar to the findings of Fauth & Gibbons (2014), appears to contradict other studies where “irritability” or “agitation” are among the *most* frequent (Cerejeira *et al.*, 2012; Prado-Jean *et al.*, 2010). This raises some questions as to how these behaviours are conceptualised across measures, and also the possibility that social acceptability may influence responses on these items.

Executive function deficits and burden

This study confirmed the hypothesis that executive function deficits, as reported on the DEX, predict carer burden after controlling for age, gender and relationship to care-recipient. In regression analyses, executive dysfunction was the most significant predictor, in line with previous research which has found behavioural symptoms in general, and executive functioning in particular, to be a major determinant of burden (Davis & Tremont, 2007; Rymer *et al.*, 2002).

Through exploring the different facets of executive dysfunction and dimensions of carer burden, this study indicates that this relationship may be more complex, in that different types of executive difficulty can result in different aspects of burden for caregivers. Disinhibition and executive memory problems, which include sequencing, confabulation and perseveration, had the most impact on caregivers’ life, while apathy and shallow affect was most predictive of caregiver guilt. Executive memory problems were most closely associated with frustration and embarrassment for the caregiver. As in the study by Springate & Tremont (2014), there were also found to be differences in the type of burden experienced by spouses and adult children. In this study, adult children were more likely to experience guilt, whereas spouses were more likely to experience frustration or embarrassment. This may reflect such issues as the amount of time spouses spend with their partner in comparison with adult children, leading to increased frustration, or the competing demands on an adult child, who may have to balance childcare or work commitments and may experience more guilt. More detailed information on whether caregivers live with the care-recipient and the number of hours of care they provide might help to clarify this. Gaining more understanding of the varying types of burden, how different types of behaviour impact on this, and those carers most likely to be

affected, may help clinicians to plan and target interventions more appropriately, as well as enabling more specific outcome measures to be developed to accurately evaluate their effectiveness. This has been highlighted as a priority by researchers in this field (Elvish *et al.*, 2013; Roach, 2013).

Causal Mechanisms

Of the potential process variables explored, this study found that caregivers who make more use of negative behaviour management strategies, such as yelling, scolding or threatening, were more likely to experience higher levels of burden. In particular, they were more likely to experience a greater impact on their life and increased guilt. This effect was found after controlling for the level of behaviour experienced. This supports the secondary hypothesis that management strategies would affect carer burden, and is in line with previous research (Lim *et al.* 2011). It is likely that the relationship between behaviour, burden and the type of management strategies used is complex and not unidirectional. However, these results indicate that, through intervening with carers on behaviour management strategies, it may be possible to reduce their burden, even without behavioural change in the care-recipient. As the link with burden is specifically around the use of negative strategies, the focus would be on reducing these. Therefore, a potential approach could involve developing caregivers' understanding of the reasons behind care-recipients' behaviours, in order to shift any negative attributions which may underlie their responses. Exploration of caregiver attributions may be a useful focus of further research in this area.

It was also hypothesised that caregivers' level of experiential avoidance would have a significant effect on carer burden. This hypothesis was less well supported. However, a significant association was found between increased use of active avoidant behaviours (AAB) and level of burden, in line with findings of Spira *et al.* (2007). In particular this was found to be predictive of caregiver guilt. AAB refers to behaviours such as using distraction to avoid experiencing negative thoughts, or avoiding asking for support if it might lead to conflict. The two subscales measuring cognitive avoidance strategies produced some unexpected results and possible reasons for this are discussed below.

Positive Aspects of Caregiving

Associations were found between the intentionality, executive memory and negative affect subscales of the DEX and lower levels of positive gain, as measured by the PAC, lending some support to the hypothesis that behaviour would impact on experience of positive gain. However, overall, executive function deficits did not account for a significant increase in variance of PAC.

The use of positive behavioural approaches, such as encouraging physical activity and arranging stimulating situations, was the most significant predictor of PAC in this study, and appears to impact on caregivers in a positive way independently of the behaviours experienced. This adds further weight to the argument that interventions focussing on helping caregivers to understand and manage their own behaviour more positively may have more impact on caregivers' quality of life than those aimed at altering the behaviours of the care-recipient.

This study has also highlighted that absence of negative strategies does not necessarily equate to increased use of positive strategies. Carers who use more positive behavioural strategies are not experiencing reduced burden as a result, but are significantly more likely to experience positive aspects of caregiving.

Conversely, increased use of negative strategies may result in significantly higher levels of burden, but will not necessarily reduce the experience of positive aspects of caregiving. This finding was also evident in the study of Tan *et al.* (2013). It appears, therefore, that burden and positive gain may be, to some extent, independent of each other, and that individual caregivers may experience high or low levels of both. For example, the finding that spouses are more likely than adult children to report frustration and embarrassment, but also positive gain, may reflect the experience of caregivers who spend long periods of time with their spouse, managing many of the frustrating and embarrassing situations that occur, but as a result of this intensity, also experience increased closeness and bond in their relationship. This also relates to the concept of experiential avoidance whereby avoiding the experience of negative emotions may also inhibit opportunities for connecting with personal values in a meaningful way. These are concepts which could usefully be explored further in order to more fully understand caregivers' experience.

Limitations

It was not possible in this study to clarify the role of experiential avoidance in carer burden and positive gain, in part due to the use of the EACQ, which had not been previously used in its English translation. The two subscales (INT and APP), which did not perform as expected in light of previous research on experiential avoidance, are concerned with the cognitive, rather than behavioural, aspects of experiential avoidance and include items such as “I can’t bear it when I get angry with my relative” and “thinking too much about what a caregiver feels and thinks about their situation is harmful”, with a positive response indicating presence of experiential avoidance. It is possible that these items have not retained their original meaning when translated from Spanish, whereas the less ambiguous behavioural items remain valid. However, it should be noted that only the AAB subscale correlated with the AAQ (Action & Acceptance Questionnaire, Hayes *et al.*, 2004), a widely used and reliable measure of experiential avoidance, in the original study reporting the development of the EACQ (Losada *et al.*, 2014), and it was suggested that the other factors may be capturing other markers of psychological rigidity, perhaps more akin to repression. Further studies are required to clarify the psychometric properties of this measure in its English version, and to explore the multidimensional nature of experiential avoidance further in this population.

Factors that have been found to impact significantly on carer burden in previous studies are the number of hours spent in the caring role each week, whether the caregiver lives with the care-recipient and the type and stage of the dementia. None of these potential confounding factors were recorded here, which limits the conclusions that can be drawn from the study.

In addition, as with most studies in this field, the study was reliant on caregivers’ report of behavioural/dysexecutive difficulties. It is likely that caregivers who experience more burden may rate the level of behavioural difficulty of the care-recipient at a higher level. Kim *et al.* (2014) compared caregiver ratings of sleep disturbance with observation and found that caregivers’ reports did not reflect the observed nocturnal patterns. Therefore this type of biased reporting may have affected results in this study.

Finally, this study relied on a sample of participants who had volunteered to take part in research. It is likely that this sample not only misses the most burdened caregivers, who may not have time or motivation to participate, but that it also represents a relatively highly educated sample. Capturing the experiences of those who are less well educated, and those who are struggling most with the care of a relative, remains a challenge for studies such as this, and it will be important to consider ways in which future studies can address this.

Further research

From these findings, behaviour management strategies appear to have an important role in the development of both burden and positive gain. The sample size in this study was insufficient to carry out a path analysis (Suhr, 2010), due to the number of parameters involved, and it was not within the scope of this study to carry out a mediation/moderation analysis. However, such analyses may be helpful in future studies in order to understand these processes more fully.

A factor which has previously been explored in relation to carer burden is the quality of the pre-caring relationship between the caregiver and care-recipient. It is likely that relationship quality may impact on burden through caregivers' responses or management strategies. Zarit *et al.*'s (1985) original model of carer burden emphasised the importance of both relationship quality and caregivers' response to symptoms in the development of burden. More recently, Steadman *et al.* (2007) found that higher levels of relationship satisfaction appeared to be associated with less reactivity to memory and behavioural problems, improved problem solving and more effective communication, as well as lower levels of carer burden. Other studies, however, have found that higher levels of relationship quality can impact negatively on caregiver wellbeing, with those who have a closer pre-caring relationship experiencing more negative emotional impact (Lewis *et al.*, 1998). This could be a potential area for future research, as there have been few conclusive findings in this field. However, accurately evaluating quality of the pre-caring relationship remains challenging, with the impact of the current situation likely to impact on caregiver and care-recipients' perceptions of this.

Further research into caregiver interventions, particularly those focussed on understanding and managing particular aspects of behaviour, is needed. As discussed, the concept of experiential avoidance and its role in development of carer burden warrants further research. However, there is some evidence from this study that active avoidant behaviour is linked with level of burden and so interventions that target experiential avoidance (such as Acceptance and Commitment Therapy, Hayes *et. al*, 2012) may be helpful.

Conclusions

This study supports the findings of previous studies in that (dysexecutive) behaviour of the person with dementia was the most predictive variable for carer burden. However, the study goes further in identifying that different types of behaviour may impact carers in different ways. The study also found that behaviour management strategies employed by caregivers were important in the development of burden and in their experience of positive gain, and a significant relationship was found between caregivers' active avoidant behaviour in relation to negative thoughts and emotions, and their level of burden. Such findings may be helpful in designing targeted interventions for caregivers.

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Journal Article 2:

Valuing the Caregiver: Development of an acceptance and commitment therapy group intervention for dementia caregivers: potential feasibility and acceptability

Word Count: 6242 (excluding abstract, tables & references)

Abstract

Objectives: This study describes the development of a new group intervention for dementia caregivers, using an ACT approach, and its potential feasibility and acceptability. The study also includes an exploratory analysis of its effectiveness.

Design: A quasi-experimental design is used involving pre- and post-intervention data from four different intervention sites, along with three month follow up data. Data on attendance, attrition and qualitative feedback was collected as an indication of acceptability.

Methods: 23 people currently caring for a family member with dementia attended the ACT group intervention for 5 sessions. Detailed evaluation forms were collected at the end of each group, along with four self-report questionnaires: Zarit Burden Interview, Positive Aspects of Caregiving Scale, Dementia Management Strategies Scale and Experiential Avoidance in Caregiving Questionnaire.

Results and Conclusions: Findings indicate that the group intervention was feasible and acceptable to caregivers, with subjective change reported in understanding of behavioural changes in the care-recipient, ability to handle negative emotions and valued living. These changes were not reflected in the outcome measures, with only one change reaching statistical significance (reduction in “intolerance of negative thoughts and emotions toward the relative”). Suggestions are made regarding possible alternative outcome measures for future studies to capture participants’ experience more fully, along with potential adaptations and future directions for the intervention.

Key Practitioner Messages

- The ACT based group programme may be a helpful intervention for dementia caregivers.
- Exploring cognitive deficits associated with dementia through experiential exercises seems to have been a particularly powerful aspect of this approach
- Measuring self-efficacy, attributions, relationship quality or valued living may capture change more accurately in future studies.
- Follow up sessions may be helpful.

Introduction

Background

The prevalence of dementia within the general population is set to increase dramatically over the coming decades, with over one million people estimated to have dementia in the UK by the year 2025 (Prince *et al.*, 2014). The associated increase in informal caregivers, providing care to someone in their own home, has the potential to add a further strain to services, as caregivers have been found to be more vulnerable to psychological morbidity (Pinquart & Sorensen, 2003) and poorer physical health (Schulz & Martire, 2004). Such negative outcomes are often associated with higher levels of carer burden (e.g. Cooper *et al.*, 2008; Pinquart & Sorensen, 2007), a construct which has also been found to be predictive of admission to residential care (Gaugler *et al.*, 2009; Spitznagel *et al.*, 2006). In addition, burden has consistently been linked with increased behavioural and psychological symptoms of dementia (BPSD), an association which is likely to be bidirectional (Riviere *et al.*, 2002; Sink *et al.*, 2006).

Existing Interventions

The need for appropriate interventions to address carer burden and wellbeing has been widely recognised in the literature and prioritised in UK government policy (NICE & SCIE, 2006; Scottish Government, 2013). The majority of interventions for this population have been derived from stress/coping models such as those of Lazarus and Folkman (1984) or Pearlin *et al.* (1990). These generally have a psychoeducational or skills building focus, aimed at building self efficacy and coping skills through increased understanding of dementia and related difficulties, and information on coping with stress. The other main approach taken in interventions for this population has been a therapeutic approach, usually based on a CBT model, aiming to modify dysfunctional thoughts around caregiving, in order to increase the use of more adaptive coping strategies and improve carer mental wellbeing.

A wealth of studies and reviews exist evaluating such interventions with mixed results. Structured psychoeducational and skills building programs have produced

some positive results in terms of improving carer wellbeing and reducing depressive symptoms (Gallagher-Thompson *et al.*, 2003; Hepburn *et al.*, 2005). CBT based therapy interventions have a smaller evidence base at present, but studies have found group interventions to be effective in reducing anxiety (Akkerman & Ostwald, 2004) and depressive symptoms (Marquez-Gonzalez *et al.*, 2007). Multi-component interventions, including elements of both approaches and delivered in more than one format (e.g. family and individual therapy) have also been developed and evaluated, with some positive effects reported (e.g. Mittelman *et al.*, 2004). The overall evidence base for interventions is mixed, with some meta-analyses and reviews highlighting promising results and the need for further development in this area (Elvish *et al.*, 2013; Gallagher-Thompson & Coon, 2007, Jensen *et al.*, 2014), while others report little or no change in measures of carer burden (Parker *et al.*, 2008; Pinquart & Sorensen, 2006).

As described above, therapeutic approaches to working with caregivers have so far focussed largely on CBT approaches, which aim to change dysfunctional thoughts and emotions around the caregiving process (e.g. Gallagher-Thompson & Coon, 2007; Marquez-Gonzalez *et al.*, 2007). A new therapeutic approach has recently been proposed in which a different focus is taken. Acceptance and Commitment Therapy (ACT: Hayes *et al.*, 2012) aims to alter the individual's relationship with thoughts and feelings, rather than altering the thoughts and emotions themselves. In ACT, it is proposed that attempting to avoid or suppress difficult or negative thoughts (experiential avoidance) leads to increased "fusion" with these thoughts, and consequently greater distress and reduced capacity for living a meaningful life adhering to personal values (Flaxman *et al.*, 2011). Experiential avoidance has been found to be linked with depression in dementia caregivers in a study by Spira *et al.* (2007), while Active Avoidant Behaviour, an element of experiential avoidance, has been found to be linked with higher levels of depression and carer burden (Losada *et al.*, 2014; George *et al.*, in preparation). ACT has been found to be effective in reducing experiential avoidance and associated emotional distress in many populations (e.g. Blackledge & Hayes, 2006; Twohig *et al.*, 2010), and has the potential to be particularly helpful in situations where distressing aspects of the

situation are unchangeable, e.g. chronic pain (Vowles *et al.*, 2009) and palliative care (Feros *et al.*, 2011).

Carer interventions based on ACT

Interventions based on ACT have produced promising results in other caregiving populations e.g. parents of children with autism (Blackledge & Hayes, 2006), support staff working with adults with intellectual disability (Noone & Hastings, 2009) and caregivers of people with acquired brain injury (Williams *et al.*, 2014). To our knowledge, the only previous published studies evaluating the use of ACT with dementia caregivers have been carried out in Spain by Marquez-Gonzalez *et al.* (2010) and Losada *et al.* (2015).

Marquez-Gonzalez *et al.* (2010) report findings from a pilot study, comparing outcomes from an eight week group intervention with a control group. A significant decrease in experiential avoidance was reported in the intervention group only ($Z = -2.38$; $p < .05$), as well as a decrease in depression and anxiety scores, although these did not reach significance (depression: $Z = -1.68$, $p = .09$; anxiety: $Z = -1.78$; $p < .08$). The study was very small ($N = 8$ for intervention and control groups), however, and so findings cannot be generalised reliably. Losada *et al.* (2015) carried out a randomised controlled trial comparing ACT and CBT for depressed dementia caregivers, with both interventions delivered on a one to one basis. They found that ACT and CBT were both superior to a control group in reducing depressive symptoms post intervention (ACT: time by treatment effect estimate = -10.47 , $t = 4.40$, $df = 179.85$, $p < .001$. CBT: time by treatment effect estimate = -8.70 , $t = 3.57$, $df = 180.46$, $p < .001$), with only CBT maintaining these at follow up. ACT was superior to CBT in reducing symptoms of anxiety (time by treatment effect estimate = -3.73 , $t = 2.01$, $df = 173.86$, $p = .046$), and only ACT was superior to a control group in reducing experiential avoidance (time by treatment effect estimate = -6.65 , $t = 2.98$, $df = 178.44$, $p = .01$). However, these changes were not maintained at follow-up. Although these results do not distinguish clearly between the effectiveness of ACT and CBT, the study only included caregivers with high levels of depressive symptomatology, with the primary outcomes being a reduction in these symptoms. As the focus of ACT is on willingness to experience symptoms while increasing engagement with values, the

use of a positive outcome measures such as quality of life or positive gain may have been more effective in capturing positive changes associated with ACT.

Evidence Base

Despite the growing number of studies into caregiver interventions, the evidence base remains modest in terms of positive outcomes for caregivers. Reasons that have been proposed for this include the heterogeneity of the population and the changing nature of dementia i.e. different caregivers will require different types of support and this will change throughout the course of the illness. It may be that many interventions are too broad or structured. Recent reviews of the evidence have highlighted the need for interventions focused around specific goals (Elvish *et al.*, 2013; Gallagher-Thompson & Coon, 2007) and tailored around the needs of individual caregivers or a common issue within a group (Brodaty & Arasaratnam, 2012; Elvish *et al.*, 2013; Zarit & Femia, 2008). Another methodological issue is the constructs targeted and measured within studies. Carer burden has been found to be a multidimensional construct and so it may be hard to shift the overall burden score within an intervention (Chien *et al.*, 2011). It has therefore been recommended that studies should also specify the proposed mechanisms of change and include these as outcome variables (Elvish *et al.*, 2013; Gallagher-Thompson & Coon, 2007; Roach, 2013).

Current Study

George *et al.* (in preparation) studied the impact of dysexecutive symptoms of dementia on three dimensions of carer burden and found that disinhibition, apathy and executive memory problems were each predictive of different dimensions of carer burden (impact on caregiver life, guilt and frustration/embarrassment). Possible mechanisms of change were also explored. The use of negative behaviour management strategies and active avoidant behaviour (an aspect of experiential avoidance) were found to be significantly predictive of burden, while use of positive strategies was predictive of positive gain. In line with the MRC guidance on developing and evaluating complex interventions (Craig *et al.*, 2008), the intervention reported in the current study builds on these findings, particularly with regard to the potential causal mechanisms of management strategies and experiential

avoidance. The study reports the development of a new intervention targeting these areas, describes the underpinning theoretical background and its potential feasibility and acceptability. Findings are reported in line with the TREND statement for nonrandomised evaluations (Des Jarlais et al., 2004).

The five session group intervention incorporates experiential exercises to help caregivers understand and connect with the experience of living with various cognitive/executive function deficits. The aim of the intervention is that, through this process, caregivers come to their own understanding of the difficulties underlying some of the behaviours they see in their family member, and of the potential functions of these behaviours. Through a collaborative process of discussion with peers within the group, they can then uncover potentially helpful strategies. It is hoped that this experience may help caregivers develop a more empathic stance, moving them toward adopting more positive, and fewer negative, behavioural approaches, consequently resulting in a reduction in burden. In addition, the use of the ACT model, and inclusion of acceptance and mindfulness techniques throughout, aims to reduce caregivers' experiential avoidance, which may in turn impact on their levels of burden and mental wellbeing and increase their awareness of, and engagement with, valued living.

Due to the multidimensional nature of the concept of burden, as described above, the study measures outcomes on separate dimensions of the Zarit Burden Interview (Zarit *et al.*, 1985), in an attempt to capture more subtle changes in caregivers' experience. In addition, possible mechanisms of change i.e. dementia management strategies and experiential avoidance, are measured. Within the ACT framework, the importance of measuring positive outcomes, as well as negative psychological consequences has been highlighted (Flaxman *et al.*, 2011), due to the nature of the intervention i.e. its focus on re-engaging with valued living, rather than targeting reduction of negative symptoms. Such outcomes have seldom been explored within dementia caregiving, and were not reported in the Marquez-Gonzalez *et al.* (2010) group intervention evaluation. For this reason, this study includes Positive Aspects of Caregiving (PAC) as an additional outcome.

This study primarily aims to assess the feasibility and acceptability of delivering the group intervention to dementia caregivers. The study also aims to gather preliminary data regarding the potential effectiveness of the intervention. It is hypothesised that following participation in the group intervention, there will be a reduction in levels of carer burden and an increase in the reported experience of positive aspects of caregiving. In addition, it is hypothesised that there will be a reduction in the use of negative behaviour management strategies, an increase in positive management strategies, and a reduction in experiential avoidance.

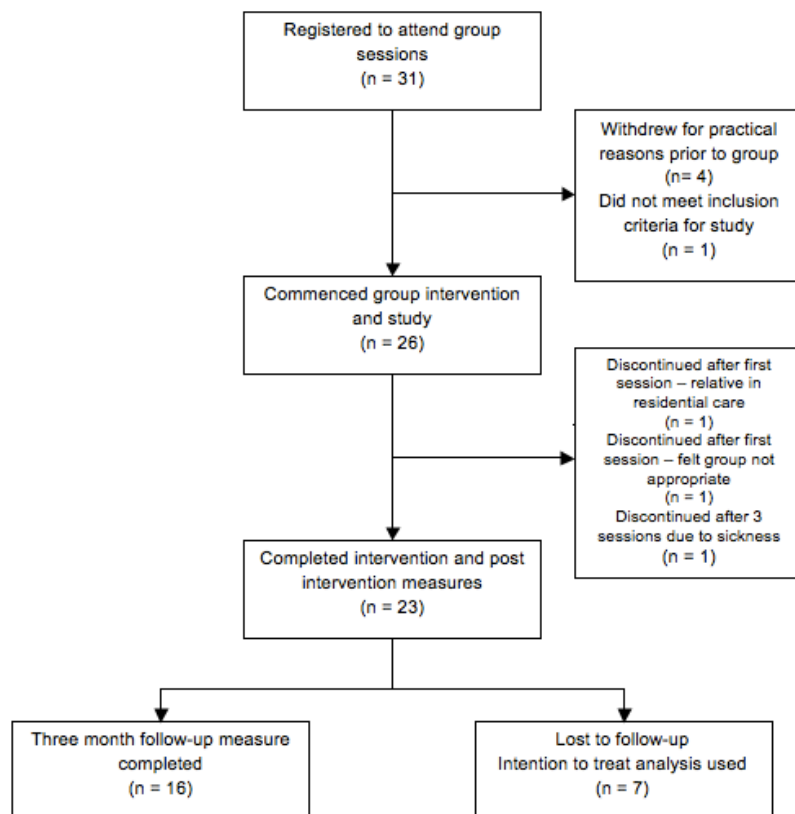
Methodology

Participants

The current study was adopted by the Scottish Dementia Clinical Research Network (SDCRN), who provided access to a database of carers throughout Scotland who had expressed an interest in participating in research. Ninety seven caregivers on the database lived within the Lothian region and were sent information about the study, together with a form to return in order to register their interest. In addition, voluntary sector carer organisations and NHS clinicians were informed about the study and passed information to caregivers with whom they were already involved. Caregivers could register for the study by contacting the first author directly or through their clinician/practitioner. Inclusion criteria were that carers had to be unpaid and caring for someone with a diagnosis of any type of dementia, who was not currently living in residential care. Thirty-one caregivers registered to attend the group sessions, four withdrew for practical reasons prior to the start of the group, two caregivers dropped out following the first session – one due to her relative being moved into permanent residential care, and one who did not feel the group was appropriate for him. One further carer dropped out following three sessions, due to illness. Twenty-three caregivers completed the course and returned post-intervention measures. One caregiver no longer met inclusion criteria for the study at the start of the course, due to her relative being in residential care, but she continued to attend the course. Sixteen caregivers returned measures at three month follow-up (see figure 1). For demographic data of those included in the study, see table 1.

Table 1: Demographic data (N=23)

	N	Mean	SD	Range
Gender				
Male	2			
Female	21			
Relationship				
Spouse	17			
Child	6			
Age of carer		66.91	10.82	46-86
Age of recipient		75.61	8.11	59-88

Figure 1: Flow diagram showing participants' path through the study

Design and Measures

The following measures were collected pre and post intervention, and were returned by post at three month follow up.

The Zarit Burden Interview (ZBI): The 22 item ZBI (Zarit *et al.*, 1985) was originally developed for use with dementia caregivers and is still the most widely used measure both for screening purposes and as an outcome measure. It has been

shown to have good validity and reliability (Cronbach's $\alpha = 0.92$; Hebert *et al.*, 2000), as well as internal consistency (e.g. Wang *et al.*, 2008).

Although very widely used, the utility of the ZBI as an outcome measure for intervention studies has been questioned (Roach, 2013). In a systematic review of intervention studies using the ZBI, Roach found that few studies reported significant change in carer burden following intervention. She proposed that one reason for this is that burden is a very loosely defined and broad concept, and that not all aspects of the ZBI have been targeted by interventions. It is highlighted that future researchers should consider the aspects of burden targeted by any intervention, as well as the proposed mechanisms of change when selecting outcome measures. This is in line with other recommendations (e.g. Elvish *et al.*, 2013). The three dimensions revealed in a factor analysis carried out by Springate & Tremont (2014) were considered most appropriate for this study, as the sample of caregivers is similar, and the dimensions are relevant to the causal mechanisms targeted within the ACT intervention. The dimensions are: impact of caring on caregivers' lives, guilt, and frustration/embarrassment.

The Positive Aspects of Caregiving Scale (PAC): The PAC (Tarlow *et al.*, 2004) was developed with a sample of 1229 dementia carers in order to assess perceived benefits of caregiving, and has been found to have good validity and reliability (Cronbach's $\alpha = 0.89$; Hilgeman *et al.*, 2007; Tarlow *et al.*, 2004). It is a nine-item self report measure consisting of positive statements about caregiving rated on a 5 point Likert scale.

The Dementia Management Strategies Scale (DMSS): The DMSS was developed to measure specific ways in which family-members manage dementia related problems, and was found to have adequate reliability and validity in a sample of family caregivers in the US (Hinrichsen & Niederehe, 1994). The scale consists of 28 self report items, and factor analysis initially indicated three subscales: criticism, encouragement and active management. Tan *et al.* (2013), found these constructs did not fit with current definitions in Singapore culture and carried out a factor analysis, resulting in the proposal of two subscales: positive and negative behaviours, and the removal of 8 items from the scale. Through assessing both papers qualitatively, it

was decided that subscales from the Tan *et al.*, (2013) study were most culturally relevant and appropriate for use in this study.

The Experiential Avoidance in Caregiving Questionnaire (EACQ): The EACQ (Losada *et al.*, 2014) is a 15 item self report measure, based on the widely used and well established AAQ (Hayes *et al.*, 2004). It has been found to have acceptable psychometric properties (reliability for the total scale is reported as Cronbach's alpha = 0.70; Losada *et al.*, 2014) and yields three subscales: Active Avoidant Behaviours ($\alpha=.63$); Intolerance of Negative Thoughts and Emotions Towards the Relative ($\alpha=.71$) and Apprehension Concerning Negative Internal Experiences Related to Caregiving ($\alpha=.60$). The measure was used to evaluate outcomes in both previous trials of ACT with dementia caregivers (Marquez-Gonzalez *et al.*, 2010; Losada *et al.*, 2015).

Detailed evaluation forms were also collected at the end of the final session (see appendix 11)

Intervention

Studies such as Feast *et al.* (2016) and George *et al.* (in preparation) have found that caregivers' reactions to BPSD may be equally, if not more, important in the development of burden or distress, than the presence or frequency of the BPSD. Therefore, the intervention had two main components, focussing on caregivers' perceptions and reactions to their situation. Firstly, the intervention had a psycho-educational component, aiming to help caregivers understand the reasons behind the symptoms they might observe in the care-recipient and focussing on a different aspect of executive dysfunction each session e.g. attention and memory, sequencing, disinhibition. Secondly, the main components of ACT were used to help caregivers normalise and accept the difficult thoughts they experience regarding the care-recipient, their symptoms and their current situation, while also supporting caregivers to clarify and reconnect with their values, through committed action. Importantly, both components of the intervention were delivered primarily through experiential exercises, in line with the ACT model (see table 2 for summary and links to the ACT model & Appendix 12 for full protocol).

Table 2: Summary of session plans

Session Number	Dementia specific exercises	ACT exercises	Elements of ACT theory addressed
1	<ul style="list-style-type: none"> Iceberg exercise – possible functions of behaviour 	<ul style="list-style-type: none"> Iceberg exercise 2 – functional analysis of own behaviour in response to thoughts and feelings Introduction to Passengers on the Bus metaphor 	<ul style="list-style-type: none"> Experiential avoidance i.e. in what ways do we avoid experiencing difficult emotions? Overarching metaphor – introduction to the model of ACT Self as context/ noticing self
2	<ul style="list-style-type: none"> Recipe exercise (attention) Memory exercise (memory and attention) 	<ul style="list-style-type: none"> Supercaregiver Exercise (adapted from Marquez-Gonzalez et al., 2010) Passengers on the Bus review 	<ul style="list-style-type: none"> Acceptance/ willingness Defusion (e.g. “is the supercaregiver a passenger on your bus?”)
3	<ul style="list-style-type: none"> Lego exercise (sequencing) 	<ul style="list-style-type: none"> Compass Metaphor Mindfulness Exercise 	<ul style="list-style-type: none"> Values Contact with present moment
4	<ul style="list-style-type: none"> Fawlty Towers Video (disinhibition) Sentence Completion Exercise (disinhibition/ response suppression) 	<ul style="list-style-type: none"> Hands as thoughts exercise Values review and Committed Actions 	<ul style="list-style-type: none"> Cognitive Defusion Values Committed Action
5	<ul style="list-style-type: none"> Communication Exercise (describe a picture for someone to draw) Group discussion on mood and personality changes, including aggression and apathy Review of iceberg 	<ul style="list-style-type: none"> Passengers on the Bus Review Letter to future self 	<ul style="list-style-type: none"> Review of model

Four groups ran weekly for five sessions. The smallest group consisted of four participants, with the largest consisting of eight. The intervention was facilitated by a trainee clinical psychologist (CG) and assistant psychologist (MB). Initial training on the protocol and ongoing supervision were provided by an experienced ACT trainer (NF), in order to ensure that the intervention was delivered with fidelity and reliability. Each session lasted two hours with additional time allowed during the first and last sessions for the completion of pre and post measures. Two groups took place within NHS settings and two in community settings, and participants were provided

with refreshments before and during each session. A group workbook was provided to all participants (see Appendix 13), from which optional home activities were set and which contained summaries of each session, to enable material from any missed sessions to be covered individually.

Data Analysis

All statistical analyses were carried out using SPSS, version 21. As seven participants were lost to follow up, intention-to-treat analysis was used, using the last observation carried forward for these participants. Little's MCAR test was carried out on the remaining missing data and did not reach significance ($\text{sig} = 1.000$). Therefore, missing values could be assumed to be missing completely at random and the Expectation-Maximisation algorithm was used to produce maximum likelihood estimates for these values (Graham, 2009).

Pre, post and follow up data was analysed using a series of one-way repeated measures ANOVA. The data met assumptions for normal distribution. A post hoc power calculation, based on the average effect size for the variables, determined the overall power to be 86%. Therefore, the sample size was sufficiently powered for parametric testing. Means were calculated for participants' ratings of each aspect of the course on the evaluation form.

Results

Potential Feasibility and Acceptability

Attendance and attrition

The overall attendance rate for those who completed the course was 89%, with an attrition rate of 11% for those who started the course.

Evaluation of Group Exercises

Participants completed an evaluation form at the end of the final session, which they returned anonymously. They were asked to rate each of the exercises/activities from the course from 0 - not helpful to 3 – very helpful. Overall, the mean rating for the exercises was 2.29 ($\text{SD} = 0.69$).

Table 5: Mean ratings for helpfulness of individual exercises

	Mean	SD
Iceberg 1	2.39	.61
Iceberg 2	2.39	.50
intro passengers	1.94	.87
Recipe	2.69	.60
memory ex	2.19	.75
supercaregiver	2.13	.74
lego	2.29	.83
values	1.79	.89
mindfulness	2.79	.43
video	2.19	.75
sentence completion	2.25	.68
hands as thoughts	2.13	.62
committed actions	2.41	.51
communication ex	2.56	.63
Discussion & review	2.44	.51
letter to self	2.07	.46

The mean rating for dementia specific exercises was 2.38 (SD=0.67) and for ACT specific exercises 2.20 (SD = 0.69). Mean ratings for the individual exercises are shown in Table 5. The exercises rated as most helpful were the mindfulness exercise and attention/recipe exercise, while the values exercise/compass metaphor and introduction to the Passengers on the Bus metaphor were rated as least helpful. These findings are discussed below.

Service user evaluation

Space was provided on the evaluation form for participants to comment on the aspects they had liked best, what they had found least helpful, areas for improvement and additional comments. Participants also had the opportunity to comment openly within the final group session. The following is a summary account of the comments made.

The qualitative feedback received indicated a high level of satisfaction and, importantly, included comments on how participants felt they had changed as a result of the course. Examples of this were: “It has helped my emotional well-being”; the

group “helped me to be able to talk about sensitive emotions”,”I have changed – I am more patient and understanding”; “it has helped me enormously in dealing with my husband’s behaviours and reactions”; “I would never have done this without the group” (booked a foreign holiday to catch up with family); “I have found my humour again”.

Overall, participants reported that the peer support they gained through sharing their experiences, thoughts and feelings with others in a similar position, was something they found very helpful. Many commented on the way in which the sharing of difficult emotions was facilitated within the group e.g. “warm, friendly encouragement”, “the relaxed atmosphere”, “getting us to express our feelings”, “no-one was judgemental”, indicating that the therapeutic context of the group was also important. With regard to the content of the course, participants reported that the group had helped with “dealing with guilty feelings” and “dealing with negative emotions”, while others focussed on the importance of making more time for themselves. Many commented on the “insight” they felt they now had into the difficulties their relative is dealing with, one participant commenting that she “had understood it on an intellectual level” before, but that experiencing it through the exercises was more powerful.

Comments on the least helpful aspects of the course were focussed around issues with members of the group sometimes dominating discussion or moving off topic, and with difficulty understanding the metaphors. However, several participants followed up these comments by noticing that the meaning of the metaphors “became clearer as the sessions went on”.

Additional comments focussed on participants’ hopes that they would be able to maintain the skills they have learned, that they will keep in touch with others they have met and that they would like the courses to be more frequent, longer and more readily available.

Exploratory Analysis of Effectiveness

Descriptive statistics

Figures 1 -4 show the mean scores on all measures at pre-intervention, post-intervention and at three month follow-up. Minimal change in the direction predicted by the hypothesis was observed on all measures at post-intervention, with the exception of ZBI: frustration/embarrassment and DMSS: positive. Changes were maintained at follow-up for ZBI: guilt, ZBI: total, PAC, EACQ: AAB and EACQ: APP.

Figure 1: Zarit Burden Interview: mean scores at pre, post and 3 month follow up

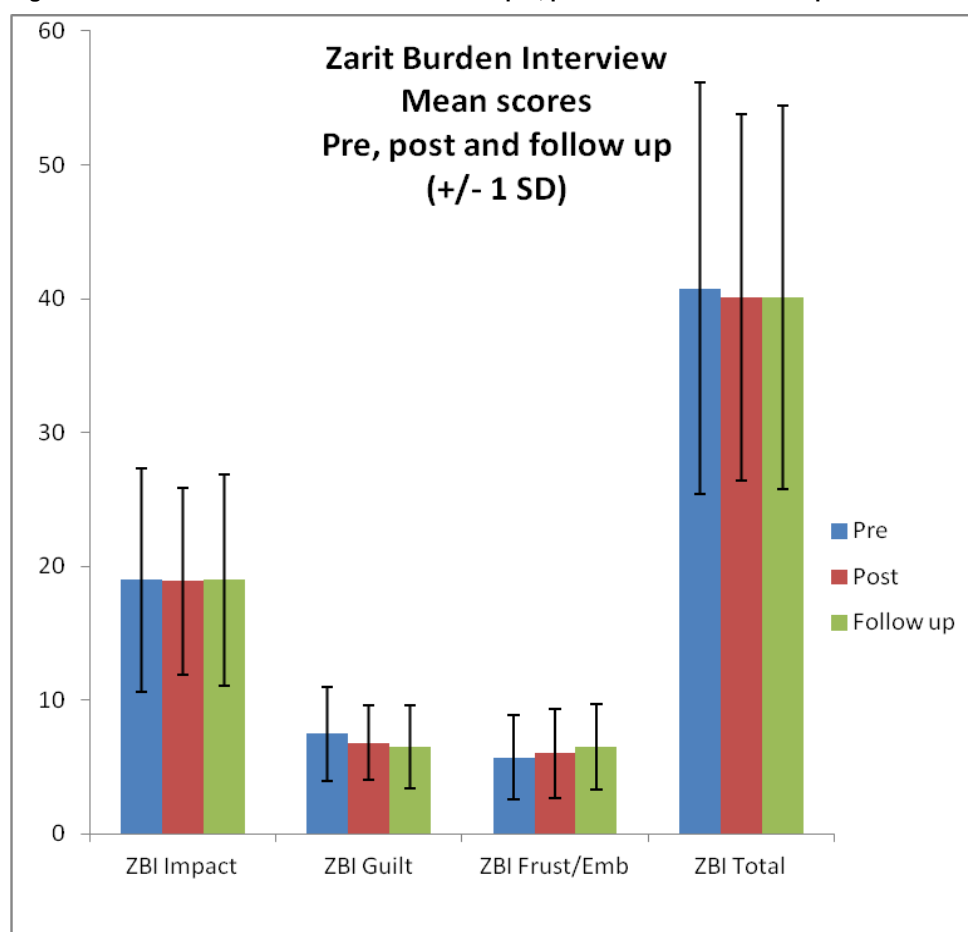


Figure 2: Positive Aspects of Caregiving Scale: mean scores at pre, post and 3 month follow up

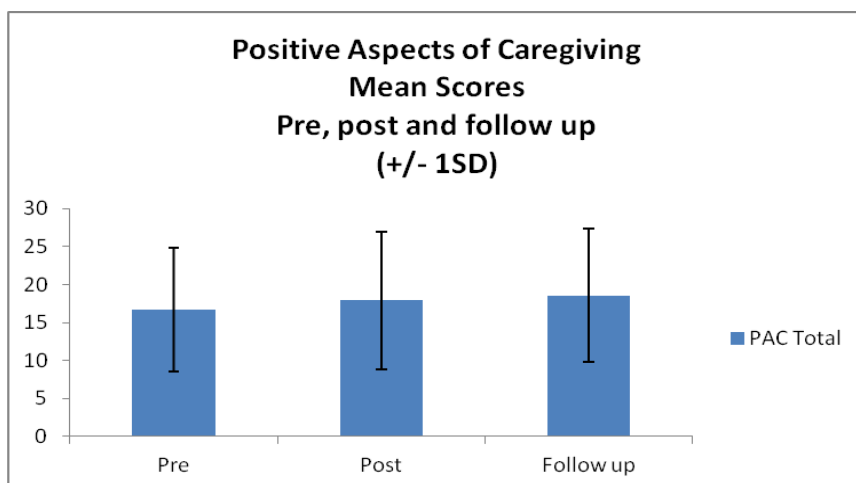
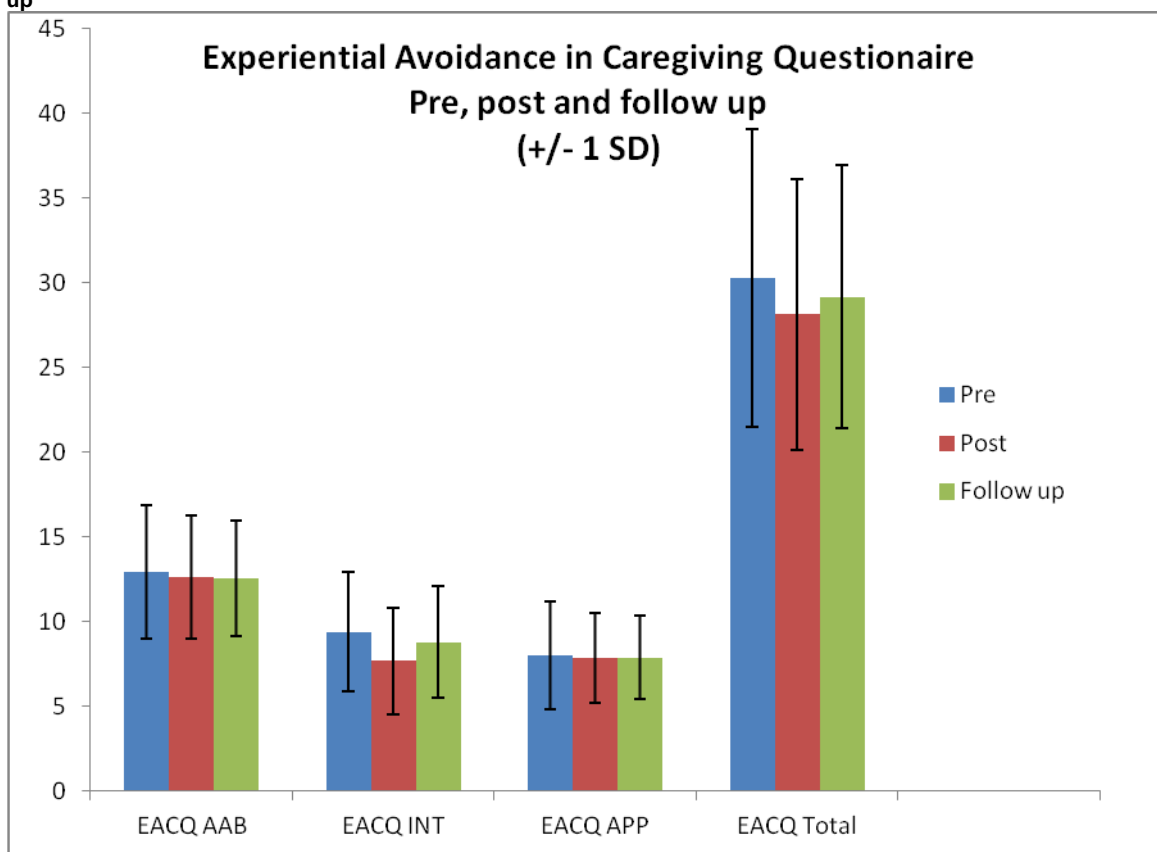
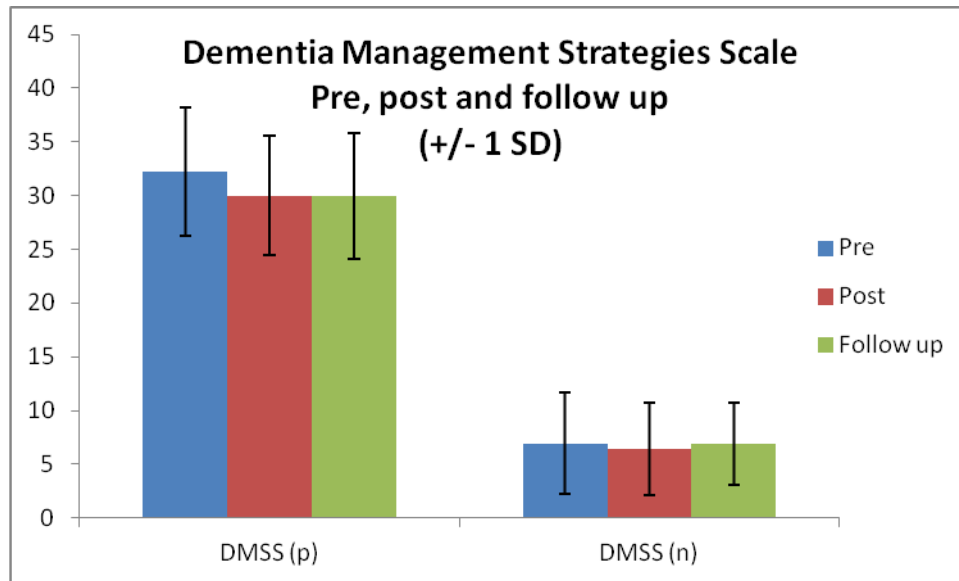


Figure 3: Experiential Avoidance in Caregiving Questionnaire: mean scores at pre, post and 3 month follow up



Dementia Management Strategies Scale: Mean scores at pre, post and 3 month follow up



Analysis of Variance

Results from the one-way repeated measures ANOVA are shown in Table 4. A statistically significant difference across time points was found for only one variable: Intolerance of negative thoughts/emotions towards relative (a subscale of the EACQ). Scores on this variable were statistically lower post-intervention, but this was not maintained at follow-up.

Table 4: Results of one-way repeated measure ANOVA across pre, post and follow-up time points

Variable	F	df	p	Partial Eta Squared
ZBI Impact on caregiver life ^a	0.004	1.45, 31.82	.98	.00
ZBI Guilt ^b	2.87	1.68, 36.99	.08	.12
ZBI Frustration/embarrassment	0.31	2, 21	.74	.03
ZBI Total ^b	0.11	1.61, 35.50	.86	.01
PAC Total ^b	0.97	1.70, 37.29	.38	.04
EACQ AAB ^b	0.13	1.67, 36.78	.84	.01
EACQ INT*	5.84	2, 21	.01	.36
EACQ APP	0.03	2, 21	.97	.00
EACQ Total ^b	1.21	1.66, 36.43	.30	.05
DMSS (p)	2.46	2, 21	.11	.19
DMSS (n)	0.31	2, 21	.75	.03

* $p < .05$, ^a Mauchly's test of sphericity was significant and $\epsilon < .75$ so Greenhouse-Geisser correction reported, ^b Mauchly's test of sphericity was significant and $\epsilon > .75$ so Huynh-Feldt correction reported

Discussion

This study aimed to describe the development of a new group intervention for dementia caregivers, based on ACT and incorporating experiential exercises designed to help improve caregivers' understanding of some of the cognitive deficits associated with dementia. The study also aimed to assess the potential feasibility and acceptability of the intervention, and to explore its effectiveness, through measuring reported levels of carer burden, positive aspects of caregiving, behaviour management strategies used and experiential avoidance pre and post intervention and at three month follow-up.

Potential Feasibility and Acceptability

This study found the group intervention to be acceptable to caregivers, with most aspects of the course rated as “helpful” to “very helpful”. Given the potential barrier of participants' caring responsibilities, the drop-out rate was fairly low (11%).

Attrition rates for psychotherapy in general have been estimated at around 47% (Wierzbicki and Pekarik, 1993), while for group therapy, figures range from 17 – 57% (Yalom & Leszcz, 2005). When compared to attrition in psychological therapy, the low dropout rate in this study provides a further indication of participants' satisfaction with the intervention.

Service User Evaluation

As described above, participants reported clearly the impact they felt the intervention had made on their lives and positive changes they had made as a consequence, indicating a high level of acceptability for the intervention. Key aspects of the intervention reported as particularly helpful, through participants' comments, were: peer support; understanding gained through experiential exercises on aspects of dementia; awareness and acceptance of difficult thoughts and emotions; behavioural change in terms of movement towards personal values. These results are in line with other ACT group interventions. Williams *et al.* (2014) found that increasing personal awareness (of emotional experiences), acceptance, and benefit of peer support were

key themes in their group intervention for brain injury spousal caregivers. Group interventions with other populations have also found peer support, ACT specific exercises and behavioural change to be important positive aspects (Johns et al., 2016).

The changes reported by participants in this study, however, were not clearly reflected in the outcome measures and so it is important to consider the reasons for this and ways in which this can be addressed in future studies. The main aims of the intervention are for caregivers to have an experiential understanding of the difficulties their relative experiences, and, therefore, potentially a deeper empathy and connection with that person. Pinquart & Sorensen (2006) found that psychoeducational interventions were the most effective intervention for dementia caregivers, but only when active participation was involved. Caregivers may experience this effect at a cognitive and emotional level in their attributions and internal responses regarding their relative's behaviour. Although this is likely to result in a reduction in negative management strategies over time, it may not result in caregivers increasing their use of positive strategies, such as the amount of physical exercise or stimulating activities they arrange for their relative. However, their feelings of self-efficacy may increase as they understand the changes in behaviour, and there may be changes in the quality of the relationship with the relative, as they develop more empathy. Previous psychoeducational interventions for this population have been effective in increasing self-efficacy (Gallagher-Thompson & Coon, 2007) and reducing negative interactions (Gallagher-Thompson *et al.*, 2003, Gerdner *et al.*, 2002). However, changes in attributions of care-recipient behaviour and changes in quality of relationship have seldom been measured, despite their established impact on caregiver wellbeing (Martin-Cook *et al.*, 2003; Quinn *et al.*, 2008).

Alongside these changes, the ACT focus of the intervention aims to help caregivers reconnect with their values, while accepting that it is normal to experience negative thoughts and emotions. Participants come to understand that attempting to avoid such thoughts can be harmful, and can reduce their potential for valued living. As discussed previously, this shift is likely to result in caregivers becoming more aware or accepting of the burden they feel, as well as allowing them to connect with the

things that are important to them, as is reflected in the quotes above. Throughout the intervention, participants were encouraged to engage in unusual exercises, with the rationale that experiencing a level of personal discomfort in order to move in the direction of personal values can be beneficial. Participants also identified that the purpose of the exercises became clearer over time. Their acceptance of these exercises and willingness to continue to engage with the group, despite some uncertainty, illustrates a level of behavioural change in line with the ACT model.

Measuring self-efficacy, attributional shifts, change in relationship quality or engagement with valued living may be helpful approaches for future studies to capture more fully the experiences described.

Changes in outcome and process variables

In line with the hypotheses, reductions were found in two of the three dimensions of burden from pre to post intervention, and there was an increase in perceived positive aspects of caregiving. In addition, all aspects of experiential avoidance reduced, as did the use of negative behaviour management strategies, such as yelling, scolding or criticising. However, only the change in the variable of “intolerance of negative thoughts/emotions towards relative” reached significance. Contrary to the effect predicted by the hypotheses, there was an increase in the dimension of “frustration/embarrassment” on the ZBI from pre to post intervention and a decrease in positive behaviour management strategies used. However, neither of these findings reached significance. There were no statistically significant changes in the variables measured between the end of the intervention and three month follow-up.

Due to the small sample size in this study, it is likely that there was insufficient power to detect a statistically significant effect, and so clear conclusions regarding effectiveness cannot be drawn from these findings. However, the results are promising and those that are not in line with the hypotheses are not entirely unexpected, given the nature of the intervention. ACT encourages acceptance of difficult thoughts and feelings, and indeed, the only significant change found was a decrease in participants’ “intolerance of negative thoughts”. Therefore, it is likely that caregivers would feel more comfortable in acknowledging and reporting their

feelings of frustration and embarrassment following the intervention, and therefore score more highly on this dimension. It is notable that the reduction in scores on the “guilt” dimension was approaching significance, indicating that caregivers may also feel less guilt for experiencing such thoughts, a further aim of ACT. In their qualitative study of an ACT caregiver intervention, Williams *et al.* (2014) identified “awareness of emotional experiences” as a key theme, quoting participants who reported that the intervention highlighted feelings they had previously tried to avoid.

In addition, another focus of the intervention was in supporting caregivers to notice when they might be striving to be a “supercaregiver” i.e. placing unrealistic pressure on themselves to do what is right for their relative at all times, but to the detriment of their own physical and mental health. Therefore, a small reduction in positive behaviour strategies without a corresponding increase in negative strategies, may simply indicate that caregivers had released themselves from some of their self-imposed pressure, or perhaps felt less pressure to produce a socially desirable response when completing the post-intervention measures, having addressed this within the group. Marquez-Gonzalez *et al.* (2010) and Williams *et al.* (2014) describe such changes in their participants, as they allow themselves to focus on their own needs, as well as those of the care-recipient, while accepting the discomfort that may accompany this.

A further positive indication from these results is that most gains were maintained at follow up, and, other than the dimensions already discussed, there were no negative outcomes at follow up when compared with pre-intervention. This is encouraging as dementia is a progressive disease, during which carers’ situations and the challenges they face are constantly changing. If these gains are maintained despite deterioration in their relative’s condition, this would suggest that caregivers have been able to continue to generalise and adapt the strategies they have learned in order to deal with their changing circumstances. However, without a control group comparison, firm conclusions cannot be drawn regarding this.

Intervention consideration

Although the majority of feedback was positive, it is notable that a significant number of participants found key components of the intervention, e.g. metaphors, difficult to understand or connect with, while others felt that the intervention should be longer. Both of these points may reflect the complexity of ACT in comparison to therapies such as CBT. In their comparison of the two interventions, Losada *et al.* (2015) highlighted the requirement to understand abstract concepts, assume counterintuitive ideas and utilise metacognitive abilities within ACT, which may require more time, effort and therapist support. The ACT intervention evaluated in their study consisted of eight sessions of individual therapy. Therefore, it is likely that these problems are even more pertinent to the current study, where therapist input was more time limited and the intervention less individualised.

It is also possible, however, that despite its inherent challenges, the group setting increases the impact and understanding of the intervention, through hearing other members of the group convey their understanding of the metaphors and experiential exercises, and how they can apply them to their similar situation. Normalising the experience of difficult thoughts and emotions can also be a quicker and more powerful process when participants hear the thoughts they have avoided being voiced by one of their peers. In addition, the support that the group provides both within and outwith sessions can be a source of comfort and reduce potential isolation for those who attend.

In the future, it may be helpful to add additional sessions to address the complexity of some of the concepts within ACT, providing opportunities to use alternative exercises and metaphors to ensure participants' understanding. As suggested by Losada *et al.* (2015), booster sessions could also be offered to support caregivers' ongoing use of the strategies learned.

Limitations

In addition to the limitations regarding outcomes measured and sample size, issues have been identified with the use of the EACQ as a measure of experiential avoidance (George *et al.*, in preparation, Losada *et al.*, 2014). The validity of the two

subscales measuring cognitive aspects of experiential avoidance (INT and APP) is unclear, and it may be that the significant reduction in the “intolerance” subscale in this study was due to the explicit discussion of issues included in this scale e.g. “It’s normal for a caregiver to have negative thoughts about the person they’re caring for”, rather than a shift in caregivers’ psychological flexibility. Further studies are needed to clarify the psychometric properties of this scale.

Results for the three month follow up stage of the study should be interpreted with caution. The last observation carried forward method was used to replace these missing values, as it is generally considered to provide a conservative estimate, reducing the risk of type I error. However, as the participants in this study are caring for someone with a progressive disease, it is possible that the follow up estimates for these participants could be inflated.

This study was not large enough to explore the differential effects of the intervention, according to factors such as age, relationship and level of burden. Future studies exploring such differences may help to clarify for whom the intervention is likely to be most effective.

Finally, as in many studies of this population, the sample consisted of caregivers who volunteered to take part, and were able to access the weekly sessions. This is unlikely to be representative of this population as a whole and may not include those caregivers who are most burdened and may not be able to take a break from their caring responsibilities. An important task for the future will be to explore the potential for effective interventions to be adapted for caregivers to access remotely.

Clinical Implications

There is currently limited empirical evidence supporting the use of ACT to reduce symptoms of depression or burden in dementia caregivers. However, this study adds to the findings of Marquez-Gonzalez *et al.* (2010), Losada *et al.* (2015) and Williams *et al.* (2014), in finding ACT a feasible and acceptable approach with promising results for caregivers. Due to its focus on accepting negative thoughts and emotions and valued living, rather than symptom reduction, it may be that ACT can have

increased utility as an early intervention or preventative measure for caregivers who experience some level of burden, but have not yet developed depressive symptoms. The group format not only provides an efficient method of delivery, but, as highlighted above, aspects of the group process appear to be crucial to the impact of the intervention for participants.

If delivered in community settings, as was the case for two of the groups in this study, the intervention may have a wider reach, with more potential for ongoing follow up sessions to maintain skills developed, aiming to reduce future referrals of caregivers to mental health services. It could also provide a valuable alternative approach for caregivers who may be less likely to access a psychological intervention, due to perceived stigma or preconceptions around this.

As interventions based on CBT have shown some promising results with this population, it will be important to carry out well designed studies to compare the effectiveness of each approach delivered in a group format across a range of outcomes. Findings from such studies will help to ensure that services can offer interventions tailored more specifically to caregivers' needs.

In addition, dismantling studies are increasingly being utilised to explore the therapeutic impact of the individual components of ACT e.g. mindfulness, values. In the future, this may be a helpful approach to explore further the potential mechanisms of change involved in this intervention. This information may not only improve the efficiency of the group intervention, but could be used to inform potential adaptations of the intervention e.g. for online use, increasing potential access for more isolated caregivers.

Conclusions

The results from this study are promising and suggest that the ACT-based group intervention delivered seems to be feasible and acceptable to dementia caregivers. Exploring cognitive deficits associated with dementia through experiential exercises seems to have been a particularly powerful aspect of this approach, increasing caregivers' connections with the people they care for.

More work is needed in considering alternative outcome measures, such as self-efficacy, emotional well-being, change in relationship quality or valued living, which may more accurately capture the processes of change highlighted in participants' subjective reports. Adaptations to the intervention and its delivery may be required in order to include those caregivers who are harder to reach.

Dissemination

Following completion of the study, a summary of the findings was posted on the SDCRN website and sent to all participants.

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Appendix 1: Quality Assessment Tool

	Background Rationale	Population/ Representative Sample	Sample Size/power calculation	Burden operationalised	Primary outcome measures	Confounding variables taken into account	Clusters of behaviour	Data analysis & results	Conclusions
Well Covered (2)	Previous relevant background literature discussed, giving logical rationale for study	Diagnosis, definition of carer and recruitment process clearly reported	A priori power/ sample size calculation carried out	Rationale given for measure used/ Subscales of ZBI	Good reliability and validity. Widely used with this population	Confounding variables (e.g. relationship to patient, gender, age) taken into account and justified (i.e. some rationale given for these)	Well established subscales used to describe clusters of behaviour OR individual behaviours specified	Appropriate statistical method described and used. Effect size reported or sufficient information to calculate	Conclusions relate clearly to findings. Limitations and wider implications discussed.
Adequately covered (1)	Some discussion of background literature related to current study	1 or 2 of the above criteria clearly reported	No a priori calculation, but power addressed post hoc	Reference made to objective/ subjective burden or difference between burden and depression etc	Some evidence of reliability and validity and use with this population	Confounding variables taken into account, but no rationale given.	A clear rationale for clusters of behaviour based on previous research	Appropriate statistical method used. Insufficient information reported for effect size to be calculated	Conclusions relate to findings, but little discussion of limitations or wider implications.
Poorly/ not addressed (0)	Theoretical rationale for study unclear	Inclusion criteria not clearly reported	No power or sample size calculation reported	No rationale given for inclusion of burden measure	Little or no previous use within this population. Lack of data on reliability and validity.	Confounding variables not taken into account	No rationale given for clusters of behaviour used	Method of data analysis unclear or not reported.	Conclusions unclear. Little discussion of limitations or wider implications.

Appendix 2: Reasons for exclusion of studies from review

Abstracts:

- Not in English
- Not “burden”
- Qualitative
- Only frequency of behaviour/ not individual symptoms
- Reviews
- Not dementia
- Intervention studies
- Nursing home/formal carers

Full Text:

Frequency/severity, but not individual behaviours/no correlation between individual behaviours and burden

Alvira (2015), Benson (2013), Bergvall (2011), Brodaty (2014), Campbell (2008), Cheng (2013), Chiatti (2015), Clyburn (2000), Coen (1999b), Coen (1997), De Oliveira (2015), Duhig (2012), Farran (1993), Fialho (2009), Fillit (2009), Frank-Garcia (2011), Gallagher (2011a), Gallagher (2011b), Garcia-Alberca (2014), Gaugler (2005), Germain (2009), Haro (2014), Harwood (2000), Hebert (2001), Hebert (2003), Hsieh (2013), Hwang (2014), Jackson (2014), Jones (2015), Kajiwarra (2015), Kannan (2011), Kim (2012), Kulaksizoglu (2011), Lima-Silva (2015), Machniki (2009), Magai (1995), Mangone (1993), Mavandadi (2012), Melo (2011), Mohamed (2010), Mohamed (2009), Moreno (2015), Mougias (2015), Ng (2012), Oh (2104), Park (2013), Park (2015), Raccichini (2009), Rosdinom (2013), Seng (2010), Shaji (2009), Shapira (2012), Shim (2013), Slachevsky (2013), Spitznagel (2006), Sutcliffe (2015), Tschanz (2012), Tun (2008), Tutar (2013), Wong (2015), Whitlatch (1999), Zarit (2010), Zarit (1980), Zhang (2014), Coen (1999a), Gitlin (2008), Hashimoto (2014), Mioshi (2009), Mioshi (2013), Mossello (2008), Nageratnam (1998), Shigenobu (2002), Springate (2014), Sultzer (2009), Vetter (1999), Yu (2015), Zahodne (2015)

Conference abstracts/dissertations – not yet published or full text not available

Aki (2014), Chae (2014), Dauphinot (2015), Dhikav (2012), Fogel (2003), Gaugler (2010), Gitlin (2007 – protocol only), Goodman (2000), Gwyther (1986 – editorial), Ransmayr (2012), Silvestre (2011), Taameeyapradit (2014), Uett (2011), Yoo (2014)

Some construct other than burden measured

Arango-Lasprilla (2009), Arbus (2008), Arriola (2005), Balestri (2000), Di Gregorio (2002), Nobilli (2004), Nogalez-Gonzalez (2015), Ornstein (2013), Riello (2002) , Sink (2006), Thyrian (2014), Wijngaart (2007)

No specific measure of behaviour included

Miller (2013), Milligan (2013), Prince (2012), Seltzer (1997), Sinha (1996), Tesar (1993), Uei (2013)

Includes formal caregivers

Aguerra-Ortez (2010), Miyamoto (2010)

Included other diagnoses

Hall (2014)

Appendix 3: Adoption Letter from SDCRN

Psychiatry of Old Age
Murray Royal Hospital
Muirhall Road
Purton
PL27 8BH
Telephone Number: 01738 562322
Fax Number: 01738 562441



Catrina George
Trainee Clinical Psychologist
Psychology Department
St John's Hospital
Howden Road West
Livingston
EH54 6PP

Our Ref
Enquiries to
Direct Line
Email

N4N 59
Philip Brown, Administrator
01738 562322
philip.brown1@nhs.net

26th January, 2015

Dear Mrs George

We have considered your study **'An exploration of executive functioning deficits in dementia as reported by family carers: links with carer burden and positive gain, potential mediators and moderators, and controlled trial of a group intervention.'** for adoption to the Scottish Dementia Clinical Research Network.

We have pleasure in informing you that the network has approved adoption of your study for the following support:

- Access to carer data
- Patient & Public Involvement

We would like to include a brief summary of your study and contact details on our website. Please let me know if this is not acceptable.

Please read and sign the attached conditions form and return it to me.

We wish you every success in your project. Please do not hesitate to contact me for further clarification and assistance when the time arises at emma.law@nhs.net.

Kind regards.

Yours sincerely

EMMA LAW
Manager
Scottish Dementia Clinical Research Network

Appendix 4: NHS Ethics Approval

Lothian NHS Board

South East Scotland Research
Ethics Committee 02

Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone 0131 536 9000



www.nhsllothian.scot.nhs.uk

Date 31 December 2014
Your Ref
Our Ref

Enquiries to: Joyce Clearie
Extension: 35674
Direct Line: 0131 465 5674
Email: Joyce.Clearie@nhsllothian.scot.nhs.uk

31 December 2014

Mrs Catriona George
1 Sycamore Place
Stirling
FK8 2PH

Dear Mrs George

Study title: An exploration of executive functioning deficits in dementia as reported by family carers: links with carer burden and positive gain, potential mediators and moderators, and non-randomised controlled trial of a group intervention.

REC reference: 14/SS/1107

IRAS project ID: 163340

Thank you for your recent letter, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Ms Joyce Clearie, joyce.clearie@nhsllothian.scot.nhs.uk. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the



Headquarters
Waverley Gate, 2-4 Waterloo Place, Edinburgh EH1 3EG

Chair Mr Brian Houston
Chief Executive Tim Davison
Lothian NHS Board is the common name of Lothian Health Board

Appendix 5: NHS R & D approval

University Hospitals Division

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ

FM/XX/approval

13 January 2015

Dr Rosalind Evans
NHS Lothian
Psychology Department
St John's Hospital
Howden Road West
Livingston
EH54 6PP



Research & Development
Room E1.12
Tel: 0131 242 3330

Email:
R&DOffice@nhslothian.scot.nhs.uk

Director: Professor David E Newby

Dear Dr Evans

Lothian R&D Project No: 2015/0002

Title of Research: An exploration of executive functioning deficits in dementia as reported by family carers, links with carer burden and positive gain, potential mediators and moderators, and non-randomised controlled trial of a group intervention

REC No: 14/SS/1107

Participant Information Sheet:

Form 2 version 2 dated 22 December 2014

Consent Form:

Form 1 version 2 dated 22 December 2014

Form 2 version 2 dated 22 December 2014

Protocol:

Version 1 dated 21 November 2014

I am pleased to inform you that this study has been approved for NHS Lothian and you may proceed with your research, subject to the conditions below. This letter provides Site Specific approval for NHS Lothian.

Please note that the NHS Lothian R&D Office must be informed if there are any changes to the study such as amendments to the protocol, recruitment, funding, personnel or resource input required of NHS Lothian.

Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the MHRA where applicable.

Please inform this office when recruitment has closed and when the study has been completed.

I wish you every success with your study.

Yours sincerely

A handwritten signature in black ink that reads 'Fiona McArdle'.

Ms Fiona McArdle
Deputy R&D Director

CC: Ms Catriona George, Chief Investigator, University of Edinburgh

Appendix 6: Participant Information Sheet – all areas



Participant Information Sheet

An exploration of executive functioning deficits in dementia as reported by family carers: links with carer burden and positive gain, potential mediators and moderators

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

It is well recognised that people who are caring for someone with dementia can experience high levels of stress and burden, which can impact on their ability to cope.

Previous research has shown that changes in personality and behaviour in people with dementia are linked with the level of stress experienced by carers. Studies have also found that the way carers think about and manage their situation can affect the way they feel. The aim of this study is to further explore how changes in the person with dementia, and the way that carers think and act in this situation can affect carers' overall level of burden/stress. It is hoped that this study will provide further information in order to develop more effective carer supports.

Why have I been asked to take part?

You have been asked to take part as you are currently caring for a partner or family member with dementia. We hope that around 75 carers will agree to take part in this study.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign one consent form per study. If you decide to take part you are still completely free to withdraw at any time and without giving

a reason. Your decision to take part will not affect the healthcare you or the person with dementia receive.

What will happen if I take part?

You will be given this patient information sheet, a consent form, a questionnaire pack and a prepaid return envelope. If you agree to take part, you are asked to sign the consent form, fill in the questionnaire pack and return them in the envelope provided. In our experience we have found that the questionnaire pack takes about 30 – 40 minutes to complete. You do not have to answer the questionnaire pack all in one go. You can fill the questionnaire pack throughout the week at your own pace if that is more suitable for you. You are asked to answer it during the following week and post it back to us. You may contact the researcher in case of changes in your contact details or interest in this study.

What are the possible benefits of taking part?

We do not anticipate any direct personal benefits from taking part in this study. However, we hope that the information we obtain from this study will help researchers and clinicians understand more about how carers' coping strategies and thinking patterns may impact on their levels of stress. This may help us design more effective interventions for carers of people with dementia.

What are the possible disadvantages and risks of taking part?

The questionnaires ask you to reflect on your thoughts and feelings about your situation, and it is possible that this could bring up difficult issues and be potentially stressful. If you think this may upset you, you are still free to withdraw at anytime and without giving a reason. If you become worried about your emotional wellbeing, please contact your GP.

Will my taking part in the study be confidential?

All information collected about you will be kept in strict confidentiality. Your questionnaire results will be identified by a special code. The data relating the code with your personal details will be kept separate from the questionnaire responses. All data is stored in secure locations and only the principal researcher will have access to it. Data will be kept for 10 years and then be destroyed.

We will ask for details of your GP and your permission to contact them should any concerns be raised regarding your welfare, resulting from your responses to the questionnaires.

What will happen to the results of the study?

The study will be written up as part of the course work for the principal researcher's Doctorate in Clinical Psychology.

The results of the study will be submitted for publication in a scientific journal and may be presented to fellow researchers and practitioners via conference presentations and posters. Your participation will not be identified in any report/publication.

You may express your interest to obtain a copy of the published results by contacting the principal researcher, Catriona George.

A summary of the results, written for participants' information, will be available following the completion of the study. Please contact Catriona George (see below) if you wish to receive this summary by email or post.

Who is organising the research and why?

The research is being organised by NHS Lothian and Edinburgh University in order to develop more effective supports for caregivers. It also forms part of the principal researcher's academic course work for the Doctorate in Clinical Psychology.

Who has reviewed the study?

The study has been reviewed by the South East of Scotland Research Ethics Committee.

If you have any further questions about the study please contact: Catriona George, Trainee Clinical Psychologist on: 07710 866751 or email: s0997568@sms.ed.ac.uk

If you would like to discuss this study with someone independent of the study team, who can help you consider the information provided and whether or not to participate, please contact: Dr Jill Cossar on: 0131 651 3952 or email: jill.cossar@ed.ac.uk

If you wish to make a complaint about the study please contact NHS Lothian: NHS Lothian NHS Lothian Complaints Team

2nd Floor

Waverley Gate

2-4 Waterloo Place

Edinburgh

EH1 3EG

Tel: 0131 465 5708

Email: craft@nhslothian.scot.nhs.uk

Appendix 7: Participant Information Sheet – Lothian



Participant Information Sheet

An exploration of executive functioning deficits in dementia as reported by family carers: links with carer burden and positive gain, potential mediators and moderators, and controlled trial of a group intervention

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

It is well recognised that people who are caring for someone with dementia can experience high levels of stress and burden, which can impact on their ability to cope. This research will involve two studies.

Study 1

Previous research has shown that changes in personality and behaviour in people with dementia are linked with the level of stress experienced by carers. Studies have also found that the way carers think about and manage their situation can affect the way they feel. The aim of this study is to further explore how changes in the person with dementia, and the way that carers think and act in this situation can affect carers' overall level of burden/stress. It is hoped that this study will provide further information in order to develop more effective carer supports.

Study 2

The aim of this study is to investigate a new intervention for carers of people with dementia. This is a group intervention to help carers understand and manage some of the behavioural changes they may notice in the person they care for. The group will be based on Acceptance and Commitment Therapy, an approach which has proven to be effective in helping people to

handle difficult thoughts and feelings, and improving quality of life, in many different situations or conditions.

Why have I been asked to take part?

You have been asked to take part as you are currently caring for a partner or family member with dementia. We hope that around 75 carers will agree to take part in study 1 and that around 60 carers will agree to take part in study 2.

Do I have to take part?

No, it is up to you to decide whether or not to take part. As discussed above, there are two studies and, although we would like as many people as possible to take part in both studies, you are free to take part in just the first study and decline to take part in the second. If you do decide to take part you will be given this information sheet to keep and be asked to sign one consent form per study. If you decide to take part you are still completely free to withdraw at any time and without giving a reason.

What will happen if I take part?

(see flow chart at end of information form for summary)

Study 1

You will be given a further copy of this patient information sheet, a consent form, questionnaire pack 1 and a prepaid return envelope. If you agree to take part, you are asked to sign the consent form and fill the questionnaire pack 1 and return them in the envelope provided. In our experience we have found that the questionnaire pack takes about 30 – 45 minutes to complete. You do not have to answer the questionnaire pack all in one go. You can fill the questionnaire pack throughout the week at your own pace if that is more suitable for you. You are asked to answer it during the following week and post it back to us. **You may contact the researcher in case of changes in your contact details or interest in this study, or if you have any questions about the study.** You will also be sent a consent form for study 2 at this point.

Study 2

If you express an interest in participating in **study 2**, you are asked to sign the consent form for **study 2** and return it in the envelope provided for **study 1**. You will be contacted by telephone by the principal researcher over the next few months to offer you a place on a group course at the venue and time most suitable for you. If you are interested in attending the group course, but unsure about care for your relative while you attend, please return the form and the principal researcher can discuss this further with you. You are free to withdraw your consent at any point. **For study 2 we will only recruit the first 60 people that return the signed consent form for this study.** We will contact you to inform you of whether or not we have been able to allocate you a place in the group.

Questionnaires for study 2

The questionnaire pack used on study 2 will be slightly shorter than the pack used in study 1. For this study, we will be comparing questionnaire scores between two groups:

1. a group of people who have attended the carers' course.
2. a group who are still waiting for the carers' course.

We will sort participants into these two groups and will let you know which group you are in. All participants will have the chance to attend the carers' course during the study.

Group 1: We will ask you to complete questionnaire pack 2 on the first day of the course. After that we will ask you to complete questionnaire pack 3 at the end of the carer course, either on the last day of the course or at home, in which case we will ask you to return it in a prepaid return envelope. Questionnaire pack 4 will be sent to you 3 months after the end of the course. We will ask you to complete this pack and return it in the prepaid envelope provided.

Group 2: You will receive questionnaire pack 2, together with a prepaid return envelope around 6 weeks before the start of the carers' course. We will ask you to complete this and post it back to us within one week. You will be asked to complete questionnaire pack 3 on the first day of the course. After that we will ask you to complete questionnaire pack 4 at the end of the carers' course, either on the last day of the course or at home, in which case we will ask you to return it in a prepaid return envelope. Questionnaire pack 5 will be sent to you 3 months after the end of the course. We will ask you to complete this pack and return it in the prepaid envelope provided.

Groups 1 & 2: We are asking you to respond on all these occasions so that we can see if there are any changes in the way you feel and how you cope before and after attending the carers' course. The time commitment for this will be 2 - 4 hours spread throughout 9 – 12 months.

The Group Intervention (Carers Group)

The intervention is a group programme, which will consist of five weekly sessions, each of which will be two hours long. All participants should aim to attend all five sessions in order to complete the course. However, if you are unable to attend any session, a workbook will be provided, covering any content you may have missed. Groups will be run in various venues on weekdays, either during the day or in the evening. You will be able to choose the venue and time most suitable for you. Tea, coffee and cake will be provided at all venues. The group will be run by Catriona George (Trainee Clinical Psychologist) and another group leader.

You will be part of a group of 9 – 12 people, all of whom are currently caring for a relative with dementia. The aim of the course is to explore some of the changes in behaviour and mood you may notice in the person you are caring for, to understand why these might be happening, and help find ways to manage these. The course will also teach you skills based

on Acceptance and Commitment Therapy (ACT). The aim of these skills is to help you deal with the many difficult thoughts and feelings that can be associated with caring for someone with dementia. The course will also involve meeting others who may be in a similar situation, something which carers often find helpful. You will not have to discuss anything you don't want to.

For more detailed information please contact Catriona George, the principal researcher (details below).

What are the possible benefits of taking part?

Study 1

We do not anticipate any direct personal benefits from taking part in study 1. However, we hope that the information we obtain from this study will help researchers and clinicians understand more about how carers' coping strategies and thinking patterns may impact on their levels of stress. This may help us design more effective interventions for carers of people with dementia.

Study 2

We anticipate that the intervention in this study may help you learn new coping strategies, and improve your quality of life. If proved to be effective, it is hoped that the course will eventually be made available to many other carers of people with dementia. The evidence gathered from this study will be an important part of that process. It will also highlight any improvements that can be made for future groups.

What are the possible disadvantages and risks of taking part?

The intervention study is based on techniques that have been proven to be helpful to carers and other groups of people WITHOUT harmful effects and is being delivered by competent professionals. You will be asked to reflect on your thoughts and feelings about your situation, and it is possible that this could bring up difficult issues and be potentially stressful. However, you will not have to share anything you do not wish to, and In the event that you feel uncomfortable with any of the aspects of the intervention you are still free to withdraw at anytime and without giving a reason.

Unfortunately, it is not possible to provide travel or other expenses to participants.

Will my taking part in the study be confidential?

All information collected about you will be kept in strict confidentiality. Your questionnaire results will be identified by a special code. The data relating the code with your personal details will be kept separate from the questionnaire responses. All data is stored in secure locations and only the principal researcher will have access to it. Data will be kept for 10 years and then be destroyed.

As study 2 involves receiving an intervention delivered by a trainee clinical psychologist from within the NHS, it is standard practice to inform your GP that you will be attending.

What will happen to the results of the study?

The study will be written up as part of the course work for the principal researcher's Doctorate in Clinical Psychology.

The results of the study will be submitted for publication in a scientific journal and may be presented to fellow researchers and practitioners via conference presentations and posters. Your participation will not be identified in any report/publication.

You may express your interest to obtain a copy of the published results by contacting the principal researcher, Catriona George.

A summary of the results, written for participants' information, will be available following the completion of the study. Please contact Catriona George (see below) if you wish to receive this summary by email or post.

Who is organising the research and why?

The research is being organised by NHS Lothian and Edinburgh University in order to develop more effective supports for caregivers. It also forms part of the principal researcher's academic course work for the Doctorate in Clinical Psychology.

Who has reviewed the study?

The study has been reviewed by the South East of Scotland Research Ethics Committee.

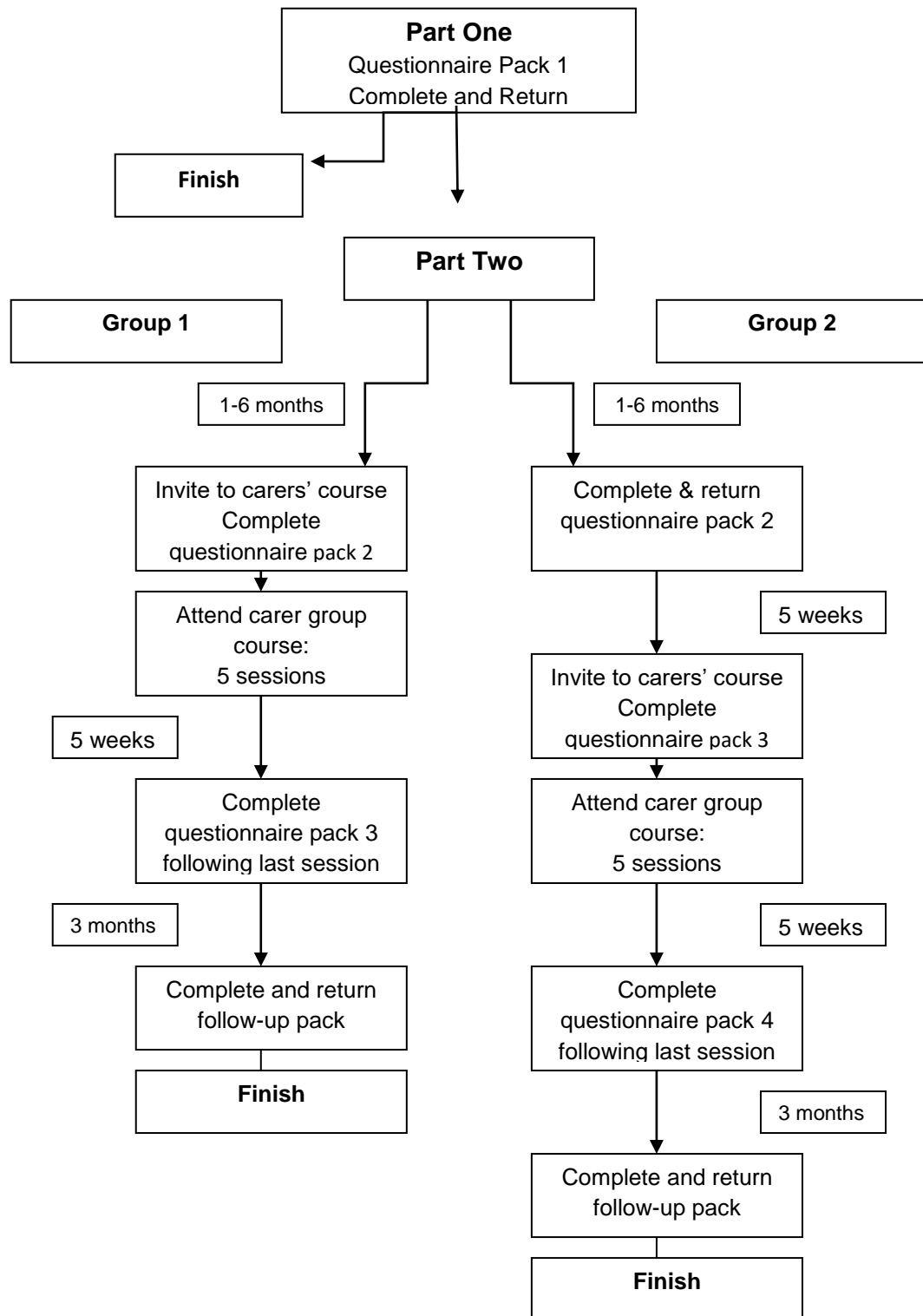
If you have any further questions about the study please contact Catriona George, Trainee Clinical Psychologist on: 07710 866751 or email: s0997568@sms.ed.ac.uk

If you would like to discuss this study with someone independent of the study team, who can help you consider the information provided and whether or not to participate, please contact: Dr Jill Cossar on: 0131 651 3952 or email: jill.cossar@ed.ac.uk.

If you wish to make a complaint about the study please contact NHS Lothian: NHS Lothian Complaints Team, 2nd Floor, Waverley Gate, 2-4 Waterloo Place, Edinburgh, EH1 3EG, Tel: 0131 465 5708 Email: craft@nhslothian.scot.nhs.uk

Flowchart detailing potential routes through the study

Participants can opt to take part in both parts of the study or part one only.
Participants for part two will be allocated to either group 1 or group 2 by the research team.



Appendix 8: Participant Consent Form – Study 1



Participant Consent Form

An exploration of executive functioning deficits in dementia as reported by family carers: links with carer burden and positive gain, potential mediators and moderators, and controlled trial of a group intervention.

Study 1 (Questionnaire pack 1 only)

Name of Researcher: Catriona George

Please initial in the boxes

1. I confirm that I have read and understood the information Sheet, version 1, dated 21/11/2014 for the above study. I have had the opportunity to consider the information and ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
3. I understand that relevant sections of data collected during the study may be looked at by individuals from the regulatory authorities and from the sponsor(s) (NHS Lothian and the University of Edinburgh), where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data. ☐
4. I am not currently involved in research into any other carer intervention ☐
5. I consent to the researcher contacting my GP, regarding my participation, if required. ☐

6. I agree to take part in this study (questionnaire pack 1 only)

☐

7. I would also be interested in taking part in study 2 (carers' group),
and would be happy to be contacted with further information about this.

☐

Name of Participant

Date

Signature

Original (x1) to be retained in site file. Copy (x1) to be retained by the participant.

Contact Details

Name:

Address:

Telephone Number:

Email (optional):

Contact Details of GP:

Appendix 9: Participant Consent Form – Study 2



Participant Consent Form

An exploration of executive functioning deficits in dementia as reported by family carers: links with carer burden and positive gain, potential mediators and moderators, and controlled trial of a group intervention.

Study 2 (Group Intervention)

Name of Researcher: Catriona George

Please initial in the boxes

1. I confirm that I have read and understood the information Sheet, version 1, dated 21/11/2014 for the above study. I have had the opportunity to consider the information and ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
3. I understand that relevant sections of data collected during the study may be looked at by individuals from the regulatory authorities and from the sponsor(s) (NHS Lothian and the University of Edinburgh, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data. ☐
4. I consent to the researcher informing my GP of my participation in the study. ☐
5. I am not currently involved in research into any other carer intervention. ☐
6. Where possible, I have discussed my participation in the group intervention with the person for whom I am caring, and they have agreed that I discuss issues about my role as their carer within the group sessions. ☐

7. I agree to take part in this study (group intervention).



Name of Participant

Date

Signature

Original (x1) to be retained in site file. Copy (x1) to be retained by the participant.

Contact Details

Name:

Address:

Telephone Number:

Email (optional):

GP name and address:

Appendix 10: Items included in DEX subscales (Burgess et al., 1998)

Subscale	DEX Items
Inhibition	<p>Response suppression problems</p> <p>Impulsivity</p> <p>No concern for others' feelings</p> <p>No concern for social rules</p> <p>Disinhibition</p> <p>Impaired abstract reasoning</p> <p>Restlessness</p>
Intentionality	<p>Planning problems</p> <p>Poor decision making</p> <p>Lack of insight</p> <p>Distractibility</p> <p>Knowing-doing dissociation</p>
Executive Memory	<p>Confabulation</p> <p>Temporal sequencing problems</p> <p>Perseveration</p>
Positive Affect	<p>Variable motivation</p> <p>Aggression</p> <p>Euphoria</p>
Negative Affect	<p>Shallow affect</p> <p>Apathy</p>

Appendix 11 – Group Evaluation Form

Evaluation Form

Each session of the course consisted of several exercises followed by some discussion. Thinking back to what you have learned from each of the exercises below, please circle the answer below which best describes how helpful you found it. Then please turn over to the final page to comment on the course as a whole.

Session 1 – Introductory session

1. **Iceberg Exercise 1** (what might be behind the behaviour you see in the person you care for)

not helpful neutral helpful very helpful

2. **Iceberg Exercise 2** (how you deal with your own difficult thoughts and feelings)

not helpful neutral helpful very helpful

3. **Introduction to Passengers on the Bus** (stickers on back of chair!)

not helpful neutral helpful very helpful

Comments on session 1:

Session 2 – Focus on Working Memory/ Attention

1. **Recipe Exercise**

not helpful neutral helpful very helpful

2. **Memory exercise** (can you remember everyone's middle name and what they did today?)

not helpful neutral helpful very helpful

3. **Supercaregiver Exercise**

not helpful neutral helpful very helpful

Comments on session 2:

Session 3 – Focus on Planning, organising, sequencing

1. **Lego Exercise**

not helpful neutral helpful very helpful

2. **Values exercise** (the compass metaphor – travelling west)

not helpful neutral helpful very helpful

3. Mindfulness Exercise

not helpful neutral helpful very helpful

Comments on session 3:

Session 4 – Focus on Disinhibition

1. Video (Fawlty Towers)

not helpful neutral helpful very helpful

2. Sentence completion exercise (Mary had a little...)

not helpful neutral helpful very helpful

3. Hands as thoughts exercise (covering face with hands)

not helpful neutral helpful very helpful

4. Committed Actions (choosing small steps towards your goals)

not helpful neutral helpful very helpful

Comments on session 4:

Session 5 - Focus on mood and personality changes

1. Communication exercise (describing a picture for someone to draw)

not helpful neutral helpful very helpful

2. Discussion of mood and personality changes/ review of iceberg

not helpful neutral helpful very helpful

3. Letter to self

not helpful neutral helpful very helpful

Comments on session 5:

Thinking about the course as a whole:

What did you like best about the course?

What did you find least helpful?

What do you think could be improved?

Any further comments:

Thank you for taking the time to complete this evaluation. 😊

Appendix 12 – Group Intervention Protocol

Intervention Protocol

Session 1

11.00

Coffee; Pre-group measures collect or fill in

Introduction to group (include The Serenity Prayer) & session plans.

Group rules

11.30

Functional Analysis of current behaviour problems: Opportunity to talk about behavioural issues most relevant to the group and what might be behind these. Use Iceberg metaphor.

12.10 – comfort break

12.15

Noticing internal feelings and thoughts and how you respond as a carer: Link functional analysis section with how carers respond when difficult thoughts/feelings come up. Bottom of iceberg – thoughts and feelings, top – how you deal with them (avoidance/trying to stop etc).

12.30

Exercise: Introduce Passengers on the Bus metaphor. Everyone writes their direction (a value) on a sheet of paper. Place on floor in front of your chair. This is where you are going on your bus (the chair). Write on post it notes some of the thoughts your mind sends you (can take some from the iceberg exercise). Stick a few to the back of your chair. What happens when you get caught up in these thoughts – turn round and argue with them, take your hands off the steering wheel etc – can you see where you are going/drive straight? What happens if you try to throw them off – they get stuck to your fingers and get even more in the way. What happens if you just leave them stuck to the back of your chair?

12.50

Homework: notice internal feelings and thoughts and how you respond to them? Using metaphor: Notice how often the passengers come up and how they stand towards them (try to ignore them, fight them, do what they tell you to do). **Fill in “Who is on your bus?” sheet in workbook.**

Session 2

Focus on: Working Memory/Attention

11.00 - Coffee

Activity: Carers are asked to give their middle name and tell the group about something they have already done today, however mundane! Carers not told that they will be asked to recall this later.

Homework review: Questions for consideration: check understanding of the activity and willingness to try. Did you notice what sort of stance you were taking towards difficult carer experiences? Was there something more prevalent? Did you find it difficult to keep track of what your mind was telling you?

11.20

Activity 2: attention exercise: in groups of three – 2 people at either side, one in the middle. The two people at either side read out different recipes to the middle person at the same time. Middle person is asked to remember the information so they could cook the meal later. Questions: What does it feel like? How would you feel if it was like that all day? What might you do? Has this exercise brought you closer to what the person you care for goes through?

Reflection on personal experiences/ what might help? Consider environment, write things down etc.

11.45

Activity 1 (review): Recall name and interesting fact: discuss steps required to attend to, process, retain and recall information

Reflection on personal experiences/ what might help? Ensuring you have attention, checking understanding, writing down, prompts, etc.

12.00 –comfort break

12.05

Homework Review 2: Reflect on how difficult it might have been to keep track of what your mind was telling you, bearing in mind the exercises today.

Passengers on the Bus: Review iceberg from last session. Have you ever had the experience of standing towards your passengers in a different way? How was that? Did it

feel that your bus was going more towards where you want to go? You have all come along to this group and are taking part in some strange exercises – this is already a way of standing differently towards your passengers.

12.20

Supercaregiver exercise & reflection: Is the supercaregiver a passenger on your bus?

Telling you what you should do? What happens when you completely give in to the supercaregiver? What happens when he/she is in the driving seat? What happens when you throw him/her out?

12.50

Homework: Notice how often the supercaregiver comes up this week. How often do you respond? What happens if you respond differently? **Worksheet in book re responding differently to your passengers?**

Session 3

Focus on planning, organising

11.00 - coffee

Homework review: Did you notice the super caregiver coming up this week or some of the other passengers? Did you try responding differently? What happened?

Activity: Other than caring for this person what else would you like to do in life, what else is important to you? Try to think of at least 1 right now. Refer to the workbook regarding possible domains. Ask them to write on a piece of paper and to keep it for later. (Leave them to think about this while you continue and tell them you'll get back to it later)

Homework review 2: did you notice yourself going back to the recipe exercise or the memory exercise from last week when the person you care for was struggling with something? How did that feel?

11.30

Activity: Sequencing difficulties: Divide the group into two or three groups to work together to build a simple lego model with instructions and picture. Mention that if someone has fine motor difficulties, they might be better as the person who oversees or reads out instructions. Allow around 10 minutes (max) for this part.

Keep the groups separate from each other, so they are not aware of each group's instructions. For the next task, one/two group(s) tries to build it with a picture but no

instructions. Second group has no instructions or picture. Allow 5 minutes for this part, even if they start to feel uncomfortable.

How did it feel? Compare with difficulty of carrying out daily tasks if steps in wrong order or forgotten how to do some steps, or what end result should be e.g. making a cup of tea, getting dressed or ready for bed. In first part, was it helpful to have someone overseeing, organising the process? Our brains have a part that does this job for us – this becomes impaired in dementia.

Reflection on personal experiences/ what might help. Verbal or visual prompts, forwards or backwards chaining etc. Discuss the potential value of allowing the person with dementia to carry out parts of the task that they can manage, even if the whole task is too much. How would you want people around you to behave if you were having these difficulties?

12.15 – comfort break

12.20

Passengers on the Bus: Go back to the question at the start. Where do you want your bus to go? What would you have to do to start getting the bus going in that direction (taking back the wheel and accepting that passengers will come along for the ride). How could you show that in real life? What sort of behaviour would you be doing that shows what you care about? If you feel that you want your bus to go in two different directions, this is normal. Just focus on the present moment and what is most important to you right now.

12.40

Mindfulness Exercise (focussing on the present moment) Go back to how busy our minds are all the time and how difficult it is to sometimes be in touch with the direction we want our bus to go in. How loud the passengers can be. Introduce mindfulness through a brief body scan. Notice what is happening in the here and now and how our minds will do their best to get us hooked. Notice it non-judgementally.

12.50

Homework: Introduce mindfulness on the go exercises (mindfully brushing teeth, washing dishes etc...) **Values clarification exercise in workbook/ Links to mindfulness exercises in workbook**

Session 4

Focus on Disinhibition

11.00 – coffee

Homework review: Mindfulness - How easy/difficult was it to do this? Did you notice your mind try to hook you in? How did you respond? Will discuss values clarification exercise later.

Did you find yourself going back to the lego task in relation to the person for whom you are caring?

11.20

Activity (video): Inhibition (impulsivity/social rules etc): Show video at the beginning to illustrate what is meant by disinhibition (Basil Fawlty – ‘don’t mention the war’).

Exercise: sentence completion (e.g. “Mary had a little...”) each person has to try to complete a sentence without saying the obvious. Go quickly round the group. How hard is it? How hard would it be if you didn’t have the ability to stop the automatic response?

Reflection on personal experiences/ what helps? Discussion of disinhibition and carers’ own experiences. Is this something you’ve noticed in the person you’re caring for?

Discussion of other aspects of disinhibition

- e.g. **ability to inhibit natural responses/ urges/ behaviours** (e.g. overeating/ hypersexuality)
- **Difficulty understanding/ remembering social rules and different behaviour required in different settings** e.g. response after hymn sung at church compared with applauding at a concert or getting up and dancing at a social event etc.
- **Not able to adjust depending on situation or person they are talking to** (e.g. inappropriate comments etc)
- **Lack of awareness of effect on others**

11.45

Exercise: Notice how you are going through the same thing as the person you are caring for i.e. thoughts pop into your head and the more you get caught up in them, the stronger they become. This is part of the human experience. Hands as thoughts exercise (cognitive defusion).

Passengers on the Bus (link this in with discussion above): What kind of passengers are trying to get your attention when these situations occur? How do you respond? What types of behaviour help you to keep the bus travelling in the right direction?

12.10 – comfort break

12.15

Homework Review 2: Values Clarification in workbook. One of them might be something around caregiving. What two, in addition to this are most important to you? Where do you want your bus to be heading?

Homework discussion and preparation: Think about where you want your bus to be heading (the type of carer you would like to be/other things that are important to you in your life). What small step(s) could you commit to taking this week that would start you moving in that direction? **Write this down in workbook and comment on how it went.**

Session 5

Focus on mood and personality changes

11.00 - coffee

Homework Review: Feedback on committed action. Praise for any small steps if they did not manage to achieve the whole thing. What barriers did you have to overcome to do this? Were any passengers shouting out?

Did you notice yourself reflecting on last week's session around disinhibition when the person you are caring for behaved in a certain way?

11.30

Mindfulness Exercise (brief): Bringing focus to what the group will be doing in the here and now.

11.35

Exercise: In pairs, facing each other. One partner has to describe to the other a picture to draw, which only they can see. They have a list of key words they are not allowed to mention (e.g. if a picture of a house, they can't mention 'house', 'square', 'roof' etc. and they are not allowed to use gestures). Discussion around how frustrated they feel, and also how it would be if they could not communicate their frustrations effectively to others and could not ask for help.

Reflections on personal experience/What might help?

11.55

Review & Discussion: Mood & Personality Changes (including aggression): Discussion of various difficulties e.g. controlling emotions, changes in motivation, lack of self awareness/insight etc. No easy strategies to avoid, but sometimes ability to predict potentially difficult situations can help. Understanding of where the behaviour comes from may help you manage your own emotions?

Also, consider responses to all of the previous difficulties – how might you respond to the sort of experiences, particularly if you had a communication impairment? This session will also serve as an opportunity to review previous session content – revisit the iceberg metaphor.

12.15 – comfort break

12.20

Passengers on the bus: Review – Where is the bus headed now? Look around the bus, notice who's coming along for the ride. What will be the next steps/committed actions you take to get where you want to go?

12.35

Letter to self (for one month's time): What are the most important/helpful things you will take away from the group? Remind yourself of where you want to be heading as a carer and in other areas of your life. What steps will you commit to taking to help you on your way? Offer your future self some words of encouragement/ helpful reminders.

12.45 – questionnaires/evaluation

Appendix 13 – Group Workbook

Group Workbook



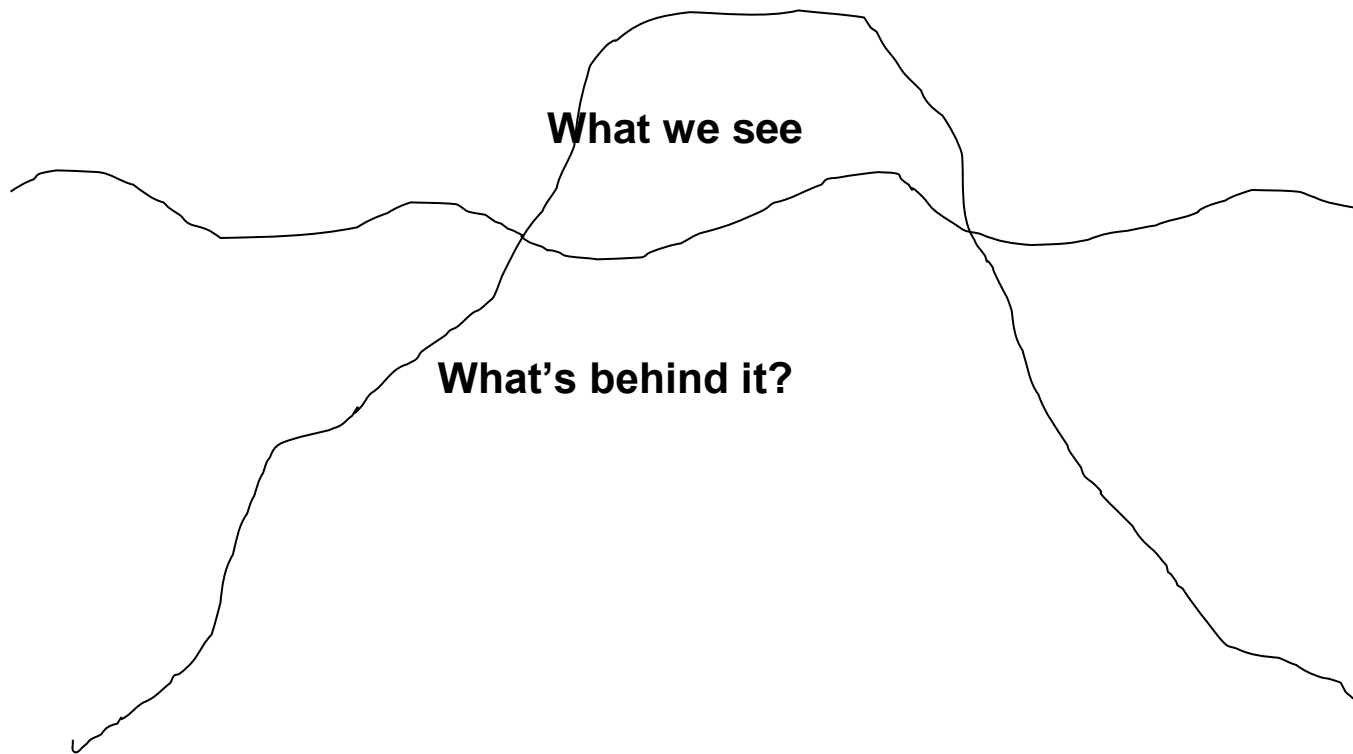
The Serenity Prayer

**Grant me the serenity to accept the things I cannot
change; the courage to change the things I can; and
the wisdom to know the difference.**

(Reinhold Niebuhr)

Session 1

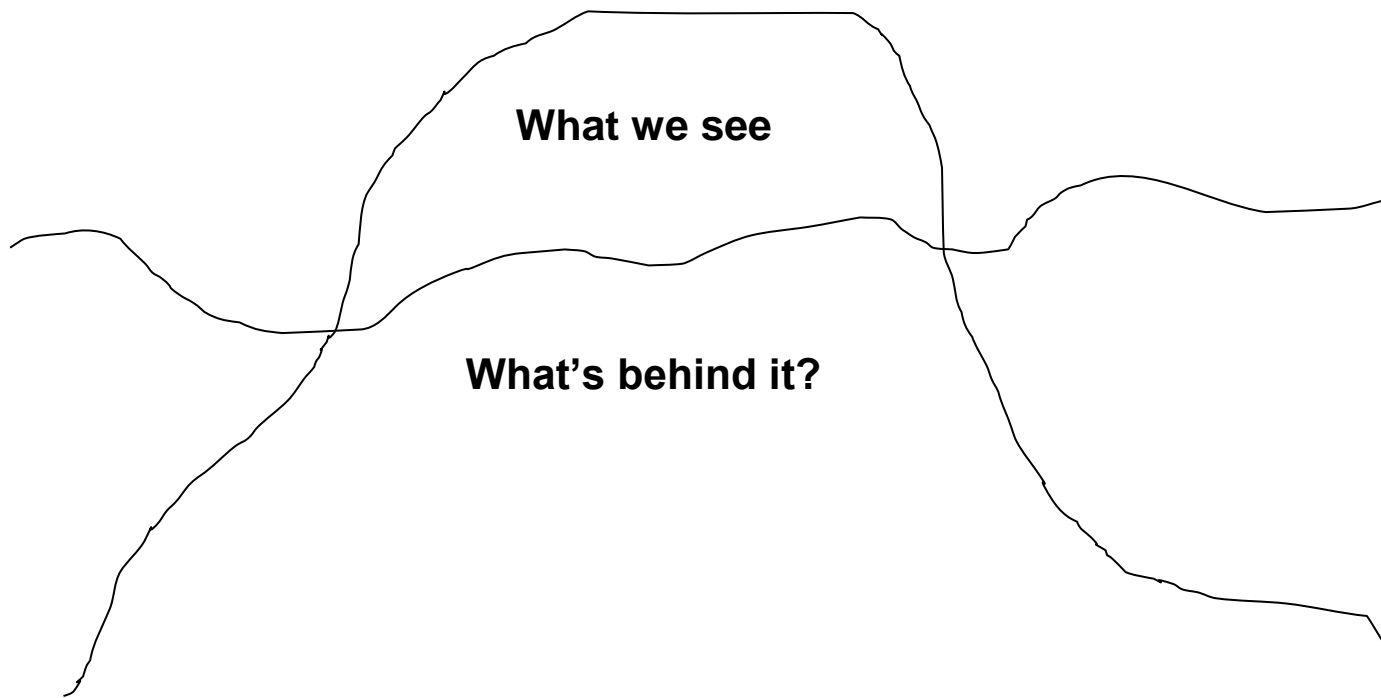
Group Exercise: Iceberg



In the group, we thought about what difficult behaviours we sometimes see in the person we are caring for. We only see the top of the iceberg. We then discussed some of the things that might be influencing that behaviour - i.e. what lies under the water.

Make a note of examples we discussed or some of your own ideas in the space below. You'll be able to come back to these later.

Group Exercise 2: Our Iceberg



The bottom of our iceberg is filled with the difficult or negative thoughts and feelings we all have to manage on a daily basis – many of these may be connected with the person you are caring for or your role as a carer. The top of our iceberg is what other people see – what do we do to deal with these thoughts and feelings or to avoid them?

Make a note of some of the things that appear at the top and bottom of your personal iceberg.

Passengers on the Bus

Group Exercise

Imagine that you are the driver of a bus heading in the direction of your values/ of what's important to you in life. Along the route you pick up various passengers. Passengers represent your experiences, your thoughts, emotions, physical sensations and responses to the journey.

Some of the passengers are very pleasant. It's great to have them along. Many are pretty neutral. But some passengers are horrible. They are ugly, loud, aggressive, threatening. They tell you you're a terrible driver. They warn you that you are going the wrong way. These passengers can be very scary to listen to. And over time, they can really get us down.

It's really hard not to listen to these passengers – they like to make themselves heard! You might try arguing with them or throwing them off the bus, but to do this you have to turn around, take your eyes off the road, take your hands off the wheel or even stop the bus. What happens then? Can you keep travelling in the direction you want to go? Does engaging with these passengers make them more or less important in our lives?

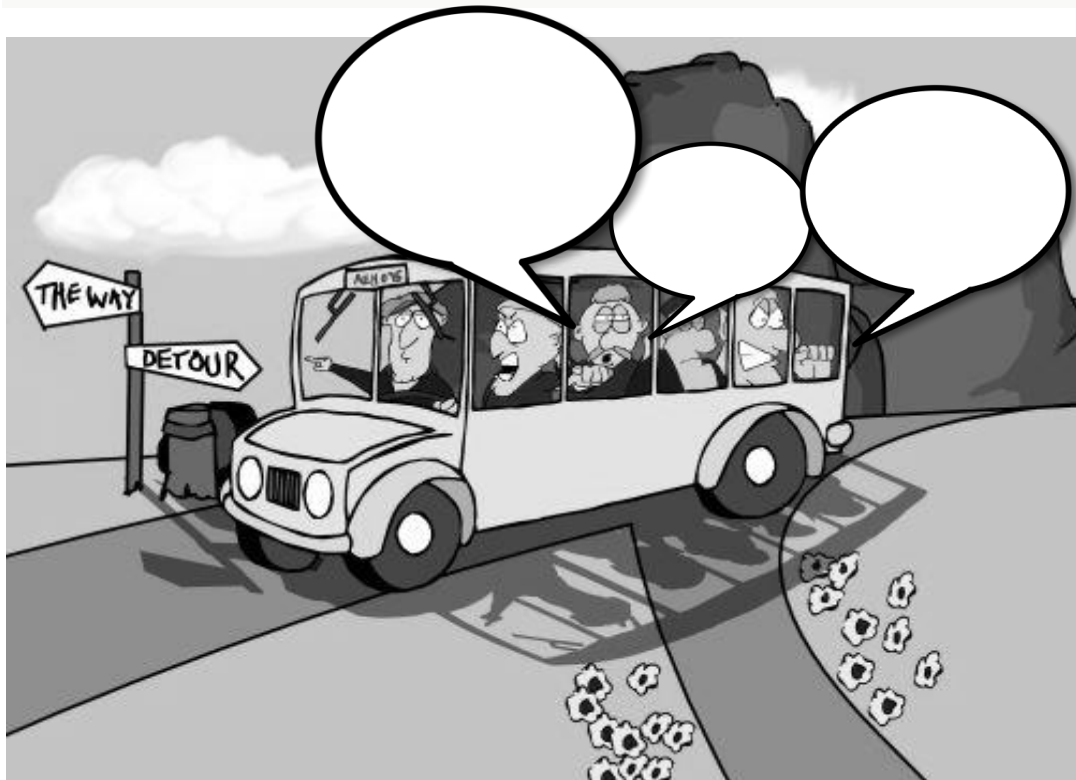
Try the exercise on the following page over the next week to help you notice your own passengers.

Individual Exercise

Who is on your bus?

This week, take some time to notice your own feelings and thoughts and how you respond to them. Notice which passengers are most persistent and how do you stand towards them? Are you getting caught up in a struggle with them? Are you trying so hard to ignore them or push them away that you lose track of where you are going?

Make a note of your passengers and how you respond. Use the speech bubbles or the space below.



My Passengers:

What they said:

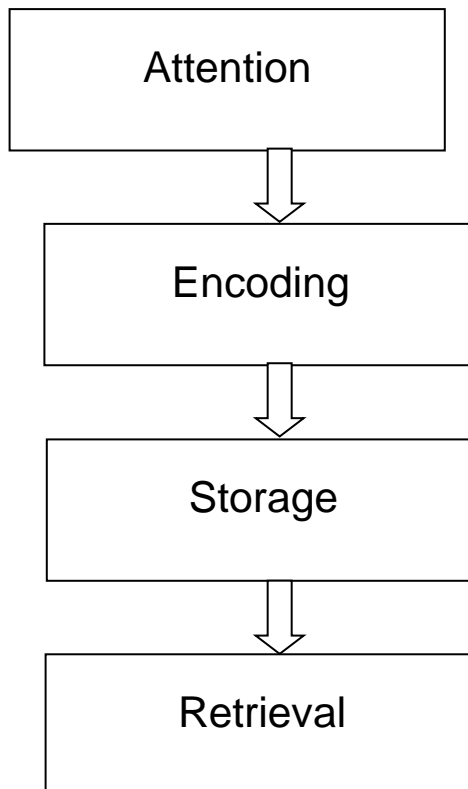
What I did (e.g. tried to block them out; tried to distract myself from them; gave in to them):

Session 2

Focus on Working Memory/ Attention

The group exercises in this session are designed to help us think about some of the different processes involved in memory, and what could happen if something goes wrong at any stage.

Memory Processes



Attention

For information to be stored in our memory, we first of all have to notice it and pay attention to it, so that we can process it. There is a vast amount of information in our environment, but we usually manage to filter out things that are not important to us, and focus our attention on the information we need to process.

This can be harder if we have problems with our vision or hearing, if we are in a very busy place with lots of distractions or if we are tired, depressed or under stress.

Encoding

Once we have successfully attended to the relevant information, our brain needs to work out what category the information belongs to in order to store it correctly.

Associating new information with information already stored is an important part of this process. So information that is personally meaningful to us, or can be easily linked with something which is already familiar is generally easier to remember.

Storage

The healthy human brain has the capacity to store unlimited amounts of information. We know that memories linked with strong emotions tend to be most resistant to forgetting, as well as memories that have been retrieved or practised many times. So memories of events such as a wedding are likely to be remembered in a lot of detail, as are skills or information used on a daily basis, for example as part of someone's job.

We also know that in disorders such as dementia, the earliest memories seem to be the most enduring, so memories of childhood are often the last to go.

Retrieval

Retrieval refers to the act of finding a piece of information from the brain when it is needed. For most information, a link is usually made instantly between the question or cue and the information required. Some information, however, requires a search around relevant categories of information. If information has been encoded correctly, this is also usually quick.

If we struggle to recall a memory, we can often be helped by clues about what was going on at the time the memory was made, or other pieces of information linked to the memory. It is also easier to recognise information we know, even though we may struggle to recall it. For example, you may not be able to recall someone's name when you see their picture, but if someone read a list of possible names to you, you would then know which one it is.

Group Exercise: Recipes

In this exercise, you are asked to remember two simple recipes (main course and dessert) in order to prepare a meal later on. However, one of the recipes is being read out loud into your right ear at the same time as the other one is read into your left ear. There are also lots of distractions in the room around you.

This task is focusing on the first memory process: attention. How would it feel if you struggled to filter out background noise or irrelevant information, and so couldn't focus on the information you were being asked to take in?

We discuss strategies that might help with this. Write these and any others you can think of here:

Group Exercise: Remembering

You are asked to remember something from earlier in the group. How easy is it if:

- Your attention wasn't focussed in the first place?
- The information wasn't linked to anything meaningful for you?
- You didn't know you had to try to remember it?
- You felt under pressure?

Think about what sort of information was easier to remember or what might have helped you with this task.

Things to try this week

Make a note of anything you think you might try differently this week following this session.

Group Exercise: The Supercaregiver

In the session we read the story of “Isabel, the supercaregiver”.

Part One: Isabel cares for her mother who has had Alzheimer’s disease for three years. She has given up her job to care for her mother, but is happy to do this, as she loves her mother and feels her mother deserves it. Isabel describes herself as “made of iron”, and always maintains a positive attitude. She “never loses her smile”, despite her mother sometimes behaving in an aggressive manner and occasionally failing to recognise her. Isabel’s siblings do not often visit or help with their mother, but Isabel understands – “poor folk, they are busy with their lives and families”. Her aim in life is that her mother is well cared for and feels loved.

Questions: What are your thoughts when you hear Isabel’s story? Do you know anybody who behaves like Isabel? Do you consider yourself to be similar to Isabel in any way? Would you like to be like Isabel? Do you think it’s possible for a caregiver to remain this positive all the time?

Part Two: In part two we hear that Isabel is not sleeping well at night, she has high blood pressure and unexplained headaches. After losing her temper with her mother during the week, she feels guilty and angry with herself. She works harder so that she doesn’t have time to think about how she is feeling. Her husband notices she is nervous and short tempered, but Isabel just smiles and says “I’m fine, with the same problems as always, but I never lose my smile”.

Discussion: What is going on for Isabel? What are the consequences of avoiding the difficult thoughts and feelings that naturally come up for her?

(Supercaregiver Exercise: Marquez-Gonzalez et al., 2010)

Passengers on the Bus



Is the Supercaregiver a passenger on your bus? Does he/she tell you what you should do? What happens when you let the Supercaregiver take the wheel? What happens when you throw him/her out?

Individual Exercise: Responding Differently

Over this week, notice how often the Supercaregiver comes up. How often do you respond? What happens if you respond differently? Use the space below to note down times when you tried responding differently to any of your passengers.

What my passengers said:

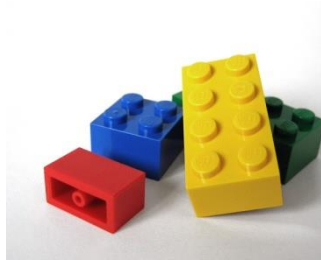
What I did differently(e.g. let them come along for the journey; stopped trying to fight with them; listened to what they have to say, but stayed on my route):

How did it feel?

Session 3

Focus on Planning and Organising

Group Exercise: Lego



In this activity, we try building a lego model under three different conditions:

1. You have a picture and step by step instructions provided
2. You have no instructions, but a clear picture of what the finished model should look like.
3. You have no instructions or picture, just bricks!

How do you feel in each situation?

People with dementia often have problems with sequencing. They may struggle to carry out daily tasks such as making a cup of tea, brushing their teeth or getting dressed, as they put steps in the wrong order, or have forgotten how to carry out some of the steps. They may also forget what the end result was supposed to be, and become stuck part way through the task.

Use this space to write down some of the strategies we discuss in the group that could help with this, or any others you can think of:

Individual Exercise: Planning a day trip

Imagine you have to plan a day trip to the museum for a group you are part of. The following are some key decisions you have to make about this trip with multiple choice responses. Circle your choices. The correct answers are on the following page. Do not be tempted to look ahead! You may feel that you have insufficient information to make a choice, but please do so anyway...and notice how this feels.

1. Which day of the week will you go on?
 - a. Monday
 - b. Wednesday
 - c. Friday

2. How will you travel?
 - a. Public Bus
 - b. Car/ minibus
 - c. Train

3. What supplies should you bring?
 - a. Packed lunch
 - b. Packed lunch and flasks
 - c. Nothing – buy drinks and food on site

4. There is an extensive outdoor area at the museum. What will you wear/bring for exploring this?
 - a. Waterproofs and boots
 - b. Hat, scarf and gloves
 - c. Sun hat and sunscreen

5. There are several special value deals available for admission to the museum. Which one will you choose?
 - a. Deal a
 - b. Deal b
 - c. Deal c

NOW TURN OVER TO SEE HOW YOU GOT ON!

Planning a day trip (follow up)

The museum is open every day of the week except Monday. It is in the middle of the city, so there is no parking nearby. The nearest car park is 1 mile away and the nearest station is 1.5 miles away. There are buses from both places though. There is a small cafe on site, which sells good value hot and cold drinks, cakes and snacks. It doesn't sell sandwiches or meals, but there is a designated area for consuming packed lunches.

Admission deals available are:

- a. Family ticket (2 adults & 2 children)
- b. Concession tickets (senior/ student/ unemployed)
- c. Group discount for groups of 8 or more

There are 10 people in your group.

Finally, it is August and the country is gripped by a heatwave!

Any easier to answer the questions with this information provided?!

Reflections: Every day we make many decisions without thinking about it. Consider how many steps and judgements are involved in planning simple trips e.g. to local shop to buy milk and bread. How difficult might that be if these abilities are impaired?

People with dementia often lose the ability to imagine the different options available to them, to think through the consequences of the decisions they make and to weigh up pros and cons of each. In combination with the sequencing difficulties explored earlier, this can make everyday tasks or trips extremely difficult, and longer term planning even harder.

Note down any further strategies discussed to help with this.

Things to try this week

Make a note of anything you think you might try differently this week following this session.

Passengers on the Bus

Individual Exercise: Where do you want your bus to go?



Consider the following questions:

Where do you want your bus to go? What sort of person do you want to be?
What personal strengths or qualities do you want to develop?

These questions tap into your values/ what is important to you. They can be hard to answer, but often people find that they can think of them in the following domains. Try writing a few words next to each heading. You don't have to share these with the rest of the group.

Work/Education



Leisure



Relationships
(family, friends,
intimate relationships)



Personal growth/health



Thing to consider: What would you have to do to start getting the bus to go in that direction? How could you show that in real life? What would you be doing that shows what you care about?

Mindfulness

In the session , we tried a mindfulness exercise to bring us into the here and now. We also discussed using mindfulness “on the go”. You could try mindfully washing the dishes, having a shower or taking a mindful walk.

If you found the body scan exercise helpful, you can find more mindfulness exercises here:

<http://www.freemindfulness.org/download>

<http://marc.ucla.edu/body.cfm?id=22>

<https://www.headspace.com>

Session 4

Focus on Disinhibition

Video and Group Exercise

We all experience thoughts, feelings and urges every day, which we immediately inhibit without thinking, as we are well aware that they would be inappropriate. Some ideas never cross our minds because we know the social rules involved.

People with dementia often lose the ability to inhibit these thoughts and responses, and, like Basil Fawlty in the video, are unable to stop themselves from saying out loud the thought that has crossed their mind. Sometimes they may be aware that it is inappropriate, but other times the person may also have forgotten some social rules and may be struggling to imagine the consequences of their behaviour (think back to the previous session).

The sentence completion group activity showed us how we can find it difficult to stop ourselves saying the first thing that comes into our heads, especially when we are feeling under pressure. Imagine how much more difficult that task would be if you were losing that ability.

Stopping our own thoughts

Don't think of a pink elephant!

What popped into your head as soon as you read that?!

In the session, we discussed how we are often going through a similar experience to the person with dementia. The more we try to push away or stop difficult thoughts and feelings, the more we get caught up in them. In the session, we tried the "hands as thoughts" exercise to show us how this can affect our experience of the world.

The exercise on the following page is another way in which we can try to separate (or defuse) from our thoughts.

Individual Exercise

Leaves on a Stream



Imagine you are sitting or standing in the middle of a stream. The water is flowing away in front of you.

Notice if there is any sound from the running water. Notice if there are any trees, etc. on the banks of the stream.

Now see leaves floating down the stream away from you. They can be any shape, colour, or size. Take every thought that comes into your mind and place it on a leaf. Do this regardless of whether the thoughts are positive or negative. Then watch them float on by.

Allow the stream to flow at its own rate. Don't try to speed it up. You're not trying to wash the leaves away – you're allowing them to come and go in their own good time.

If a leaf gets stuck, let it hang around. Don't force it to float away.

From time to time your thoughts will hook you and you'll lose track of the exercise. This is normal and natural. As soon as you realise it's happened, gently acknowledge it and start the exercise again.

(Russ Harris)

This exercise helps us to observe our thoughts coming and going without reacting to them, judging them, trying to hold on to them or pushing them away.

If you find this exercise helpful, you can find it here:

<http://drluoma.com/media/Leaves%20on%20the%20stream.mp3>

Individual Exercise: Taking Action



Last week you spent some time thinking about where you want your bus to be heading/ what are things that are important to you?

This week, commit to two or three small steps that would start you moving in that direction and that are achievable right now. Note them down here, along with your progress.

Committed Actions

Value	What achievable step will I take this week?	How did it go?

Session 5

Focus on Mood and Personality Changes

Group Exercise: Communication Frustration!



In this exercise, you will be working with a partner. One of you has to describe a simple picture to the other, who cannot see it. They then have to reproduce it based on the description. There are a list of key words they are not allowed to use. Gestures are not allowed either.

How does it feel when you struggle to make yourself understood? What if you were trying to communicate something important e.g. trying to tell someone what you needed or to tell them you were uncomfortable or in pain? What else might you try if you couldn't get your message across?

What is it like from the other side – knowing that the person is becoming frustrated with you, but being unable to understand what they are trying to communicate and so unable to help them?

People with dementia often become impaired in their communication skills. This can lead to emotions such as frustration, anger and helplessness within the relationship, which may in turn lead to more distressed behaviour from the person you are caring for.

Make a note of some of the strategies we discuss in the group that could help with this, or any others you can think of:

Group Discussion & Review

Mood & Personality Changes & Review

During this session we reviewed the iceberg from the first session and how the difficulties we have covered so far might affect someone's mood or personality and the behaviour we see. We also discussed how this could be made worse by difficulties with communication.

In addition to these difficulties, changes in the brain of the person with dementia can cause problems with:

- controlling emotions (you may notice exaggerated emotional reactions or the opposite – the person may appear quite flat in mood)
- lack of self-awareness or insight into the changes
- lack of concern for others' feelings
- changes in motivation – difficulty getting started on a task or activity/ becoming stuck or fixated on something, difficulty moving on
- aggression

Hopefully, throughout the course, you will have picked up some practical strategies to help manage or limit some of the challenges these difficulties can bring. However, sometimes this won't be possible and it is important to remember why the person you are caring for might be behaving in this way, to be prepared and to have some strategies to deal with the emotions this can bring up for you.

During this course, you have learned some techniques for handling your emotions. These come from an approach called Acceptance and Commitment Therapy (ACT). People usually find some of the exercises more helpful than others. Now that you have come to the end of the course, it is a good time to review this workbook and consider which aspects have been most meaningful and helpful to you.

Review

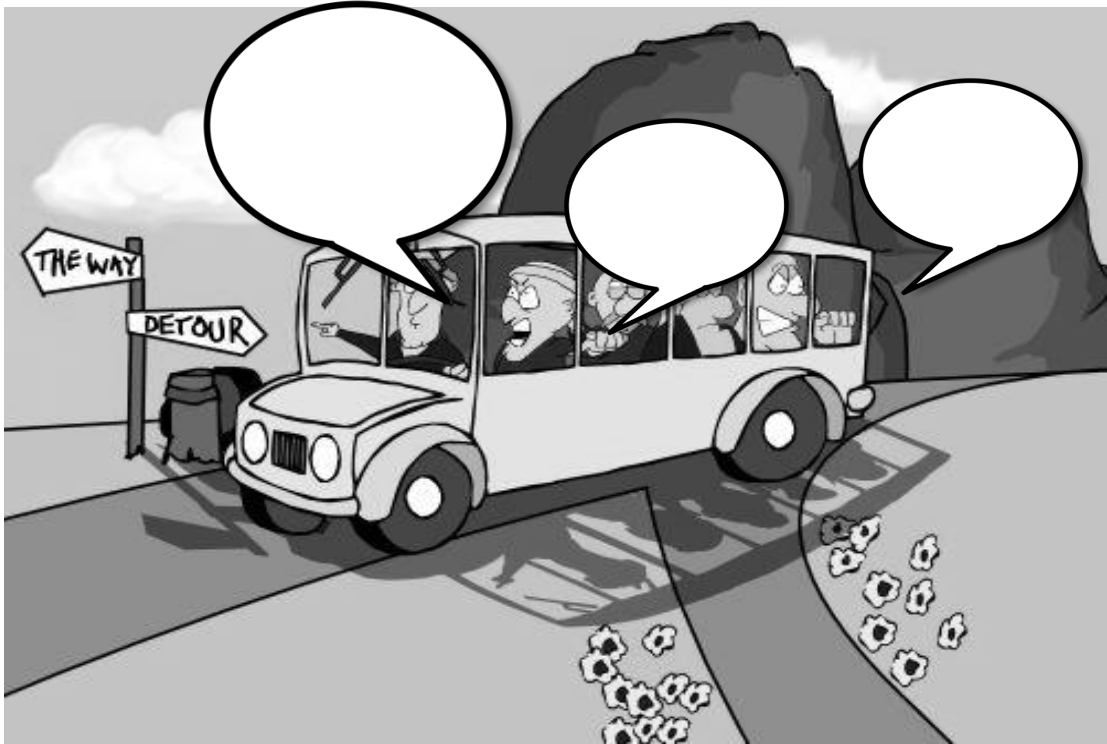
Use this space to make a note of anything you have taken from this course which you feel will be particularly helpful to remember and come back to in the future. The headings below may help to organise these.

Understanding and coping with dementia

Handling difficult thoughts and feelings

Passengers on the Bus

Next Steps



Now that the course is at an end, where is your bus heading? Look around the bus again and notice who is coming along for the ride. What will be the next steps/committed actions that will take you where you want to go?

1.

2.

3.

Appendix 14: Author Instructions – Journals

Page 175: International Psychogeriatrics (Systematic Review)

Page 185: Aging and Mental Health (Journal Article 1)

**Page 187: Clinical Psychology and Psychotherapy (Journal Article
2)**

International Psychogeriatrics

Please read these instructions carefully before submitting articles. Articles which are not prepared in accordance with these guidelines will be returned to authors unreviewed.

Scope and contributions

International Psychogeriatrics is written by and for those doing clinical, teaching, and research work with elderly people. It is the official journal of the International Psychogeriatric Association (IPA) and is published by Cambridge University Press, Cambridge, UK. Although it is concerned primarily with psychogeriatrics, the journal welcomes contributions from all concerned with the field of mental health and aging. Original research papers are particularly sought.

Contributions include original research articles, reviews of the literature, "for debate" articles, case reports, letters to the editor, book reviews and editorials. Apart from editorials, "for debate" articles and book reviews, which are commissioned, contributions to *International Psychogeriatrics* are spontaneously written and submitted by authors. Papers are reviewed by at least two expert reviewers selected by the Editor-in Chief. At present about half of the papers submitted are accepted for publication in this journal which is published twelve times per annum. The journal's Science Citation Index Impact Factor (2014) is 1.934. Submission of a paper implies that it is neither under consideration for publication elsewhere, nor previously published in English. Manuscripts must be formatted double-spaced with ample margins on all sides and the pages should be numbered. Please leave a spare line between paragraphs to enable typesetters to identify paragraph breaks without ambiguity. *International Psychogeriatrics* uses the spelling of American English. Manuscripts written by those whose primary language is not English should be edited carefully for language prior to submission. *International Psychogeriatrics* has a Language Advisory Panel of English speakers willing to check manuscripts for style prior to submission. Details can be found at both the journal website (<http://journals.cambridge.org/ipg>) under the related links icon and the IPA website (<http://www.ipa-online.org/>).

Submission of manuscripts

Note: It is not acceptable to submit to the journal an article that has previously been published or submitted elsewhere. Authors are required to assert that they have not submitted their article elsewhere upon submission to *International Psychogeriatrics*.

Manuscripts should be submitted online via our manuscript submission and tracking site, <http://mc.manuscriptcentral.com/ipg>. Full instructions for electronic submission are available directly from this site. If you are unsure of the suitability of your manuscript, please e-mail the abstract to the Journal Office before submitting online: ipaj-ed@unimelb.edu.au

To facilitate rapid reviewing, communications for peer review will be electronic and authors will need to supply a current e-mail address when registering to use the system.

When submitting your manuscript you will need to supply:

A cover letter, the manuscript with the text file in MS Word format, and all figures in TIFF or JPEG format. If the paper reports the results of a randomized controlled trial please ensure that it conforms to our requirements listed below under the heading 'Submission of randomized clinical trials' on page 2. If the research was paid for by a funding organization, the cover letter must contain the following three statements (this information does not have to be included in the manuscript itself but only in the cover letter). If the research was not paid for by a funding organization only the third statement is required:

1. That the authors have not entered into an agreement with the funding organization that has limited their ability to complete the research as planned and publish the results.
2. That the authors have had full control of all the primary data.
3. That the authors are willing to allow the journal to review their data if requested.

Submission of a manuscript will be taken to imply that all listed authors have seen the final version and approved it.

All papers will be assessed by two reviewers. If their opinions are too disparate to permit the Editor-in-Chief to make a decision on publication or the reviewers are unable to make clear recommendations, the paper will be assessed by a third reviewer. **The Editor-in-Chief's decision to accept, reject or request revision of the paper for publication will be final.** The abstract and author details will be seen by prospective reviewers of the manuscript. Authors can suggest the names and contact information of experts qualified to review the work, but the Editor-in-Chief is not obliged to follow these suggestions. Papers must bear the authors' names, titles (e.g., Dr, Professor, etc.), affiliation(s), and address(es). This information will be seen by reviewers. Reviewers' names will not be supplied to authors unless a reviewer asks to be so identified. Authors will be provided with a copyright transfer form to sign after acceptance of the manuscript, consenting to publication of the paper in *International Psychogeriatrics*.

The receipt of all submitted papers will be acknowledged. Authors who do not receive an acknowledgement of receipt of their paper within three weeks of submission should assume that their paper has not been received and should contact ipaj-ed@unimelb.edu.au, Professor Nicola Lautenschlager. Academic Unit for Psychiatry of Old Age, Department of Psychiatry, The University of Melbourne, RMH Royal Park Campus, 34-54 Poplar Road, Parkville, Victoria 3052, Australia, Tel: +61 3 8387 2326, Fax: +61 3 8387 2667. Most authors can expect to receive an initial decision on the fate of their paper together with referees' reports within no more than 100 days of submission. Authors who have received no further communication 120 days after acknowledgment of receipt of their article should contact ipaj-ed@unimelb.edu.au.

Submission of papers reporting randomized controlled trials

In order to ensure the public availability of the results of randomized controlled trials, the International Committee of Medical Journal Editors has suggested that all such trials should be registered. In common with many leading medical journals *International Psychogeriatrics* has decided to follow this policy. Since 31 December 2006 we will not review any paper submitted to us reporting a randomized clinical trial unless the trial was registered in a public trial registry from the date it commenced recruitment or, if recruitment started before 30 November 2006, we require that the trial was registered no later than 30 November 2006. For further details on the reasons for this policy see the June 2006 editorial, Ames, D. (2006). Registration of Clinical Trials submitted for publication in *International Psychogeriatrics*. *International Psychogeriatrics*, 18, 191-193.

All manuscripts reporting randomized controlled trials should have the following sent with them or they will be returned to the authors.

- a. A check list and flow chart in accordance with the CONSORT guidelines which can be found at <http://www.consort-statement.org>. Please send in the checklist as a supplementary file and include the flow chart as Figure 1 in the manuscript.
- b. The trial protocol is to be submitted as a supplementary file. This will not be published but it is needed to appraise and peer review the paper.
- c. The registration number of the trial and the name of the trial registry in which it was registered. Please add these to the last line of the paper's structured abstract. Trials that began enrolment of patients after 31 December 2006 must have been registered in a public trials registry at or before the onset of enrolment to be considered for publication in *International Psychogeriatrics*. Trials that began enrolment prior to 30 November 2006 must have been registered no later than that date. Our criteria for a suitable public trial registry are: free to access;

searchable; identification of trials by unique number; free or minimal cost for registration; validation of registered information; inclusion of details to identify the trial and the investigator within the registered entry (including the status of the trial); research question; methodology; intervention; and funding and sponsorship disclosed.

Organization and style of research articles

Title page and corresponding author: Each article must have a title page with the title of the article, a list of all authors and their titles, affiliations and addresses. Each author must select only ONE country as their location. Author qualifications should not be listed as these are not published in the journal. The title page should explicitly identify the author to whom correspondence about the study should be addressed and that author's email address, telephone number, fax number and postal address must be clearly stated.

Abstract: Abstracts for original research and reviews should be structured and incorporate 4 sub-headings: background, method(s), results, conclusion(s). Abstracts for protocol only papers should omit the third sub-heading (Results). Abstracts for case reports should have no sub-headings. Abstracts should communicate the primary findings and significance of the research. They should not exceed 250 words in length.

Key words: Under this heading and beneath the abstract, please list up to 8 words for the purpose of indexing.

Running title: This should contain no more than 50 characters including spaces.

Introduction: Briefly state the relevant background to the study to provide the necessary information and context to enable non-specialists to appreciate the objectives and significance of the paper. Most introductions to articles received for review are too long.

Methods: Materials and procedures should be described in sufficient detail to enable replication. Any statistical procedures used should be outlined and their use should be justified here. Results should not be included in the Method(s) section. If statistical procedures are used, they should be described here in adequate detail. Choice of statistical technique should be justified including some indication of the appropriateness of the data for the technique chosen. Adequacy of the sample size for the statistical technique(s) used must be addressed. If appropriate, a description of the statistical power of the study should be provided. If multiple univariate significant tests are used, probability values (p-values) should be adjusted for multiple comparisons, or alternatively a multivariate test should be considered.

Further advice about statistics and *International Psychogeriatrics* can be found in the following article: Chibnall, J. (2000) Some basic issues for clinicians concerning things statistical. *International Psychogeriatrics*, 12, 3-7. The following article may also be of assistance to intending contributors: Chibnall J.T. (2004). Statistical audit of original research articles in *International Psychogeriatrics* for the year 2003. *International Psychogeriatrics* 16, 389-396. Both of these are available at the *International Psychogeriatrics* website by following the link to [Statistical Advice for intending contributors](http://journals.cambridge.org/ipg). This is also located under the related links icon at the journal homepage (<http://journals.cambridge.org/ipg>).

Results: This section may contain subheadings. Authors should avoid mixing discussion with the results. Sample sizes should be delineated clearly for all analyses. Some indicator of variability or sampling error should be incorporated into the reporting of statistical results (e.g. standard deviation, standard error of the mean). Wherever possible an indicator of effect size (e.g. Cohens d, η^2 , Cramers V, 95% confidence interval) should be reported in addition to p values. If multiple univariate statistical tests are used p values should be adjusted for multiple comparisons or alternatively a multivariate test should be used. Obtained statistical values for tests should be reported with degrees of freedom (e.g. t, F, χ^2).

Discussion: Interpretation of the results with respect to the hypothesis(es) and their significance to the field should be discussed here. Results should be interpreted in the light of the size of the effect found and the power of the study to detect differences. Any methodological weaknesses of the

study should be outlined, including limitations imposed by sample size. Careful consideration of the conclusion(s) for accuracy and alternative interpretation, and possible conflicts or resolution of conflicts in the field is encouraged. Limited speculation and directions for future research can be included.

Conflict of interest declaration: This section must be completed. This should follow the discussion and precede the references. Where there is no conflict of interest perceived to be present the heading Conflict of Interest should be included with the single word “none” underneath it. For full details see below.

Description of authors' roles: This section must be completed if the paper has 2 or more authors. It should contain a very brief description of the contribution of each author to the research. Their roles in formulating the research question(s), designing the study, carrying it out, analysing the data and writing the article should be made plain. For example: H. Crun designed the study, supervised the data collection and wrote the paper. M. Bannister collected the data and assisted with writing the article. N. Seagoon was responsible for the statistical design of the study and for carrying out the statistical analysis.

Acknowledgements: Any acknowledgements other than conflict of interest declarations in regard to sponsorship should be listed briefly here.

References: No more than 30 articles that have been published or are in press should be cited. If authors believe that more than 30 references are essential this must be justified in the cover letter. Unpublished data, personal communications, and manuscripts submitted for publication should be cited in the text and the supporting material submitted with the manuscript. *International Psychogeriatrics* uses the Harvard referencing system. Within the text of each paper journal articles should be cited in the style (Smith and Jones, 1999). Where an article quoted in the body of the text has more than two authors the term “*et al.*” should be employed, i.e., (Smith *et al.*, 1999). Text citations of multiple articles should be separated by semicolons, i.e., (Smith and Jones, 1999; Smith *et al.*, 1999). At the end of each paper, all cited references should be listed alphabetically in the style indicated below. If the Digital Object Identifier (doi) is known, it should be added to the reference.

For a journal article: Smith, J., Jones, W. I. and Doe, J. T. (1996). Psychogeriatrics for pleasure and profit: an expanding field. *International Journal of Unreproducible Results*, 3, 240–242.
doi:12.3456/S123456789.

For a book: Smith, J.A., Brown, P.Q., Jones, H.A. and Robinson, D.V. (2001). *Acute Confusional States*. New York: Cambridge University Press.

For a book chapter. Park, K., Tiger, B. and Runn, F. (1999). Psychogeriatrics in context. In G. Verdi and A. Boito, (Eds.) *New Medical Specialties* (pp. 240–260) Cambridge: Cambridge University Press.

Where an article or book chapter has more than six authors only the first author's name should be given followed by the words “*et al.*”.

For further examples of reference style see papers in recent issues of *International Psychogeriatrics*.

Figures/Tables: The manuscript should contain no more than five figures or tables. The copies submitted with the manuscript must be of sufficient quality to enable reviewers to evaluate the data. The journal has a small budget to permit some colour to be printed in some issues but authors wishing to publish figures requiring colour to communicate the data *may* be required to pay some or all the additional cost.

Figure/Table legends: Each caption should begin with a brief description of the conclusion or observation provided in the figure. These should be submitted as a separate section after the References.

Supplementary material: More detail about the submission of supplementary material is available below – see “Supplementary Material for online only publication” and “Instructions for contributors – Supplementary Material” in subsequent pages of this document.

Word limits: At present *International Psychogeriatrics* does not have a fixed word limit for articles, but because of limited space, short articles have a higher chance of acceptance than longer ones of an equivalent standard.

Conflict of interest

Conflict of interest occurs when authors have interests that **might** influence their judgement inappropriately, regardless of whether that judgement is influenced inappropriately or not. *International Psychogeriatrics* aims to conform to the policies of the World Association of Medical Editors in regard to conflict of interest. For full details please see the website <http://www.wame.org/wamestmt.htm#fundres>. To this end all authors must disclose potential conflicts of interest so that others may be aware of their possible effects. Specifically, under the heading conflict of interest, all articles must detail:

The source(s) of financial support for the research (if none, write "none").

A description of any sponsor's role(s) in the research (e.g., formulation of research question(s), choice of study design, data collection, data analysis and decision to publish).

Information about any financial relationship between any author and any organization with a vested interest in the conduct and reporting of the study. For example, in a study on the effects of a drug made by *Bigpharma* which directly competes with another drug made by *Megadruga* declaration might say "Jane Smith has received research support and speaker's honoraria from *Bigpharma* and has received financial assistance from *Megadruga* to enable her attend conferences."

Reviews of the Literature

International Psychogeriatrics will publish at least 1 literature review in each issue. Authors intending to submit a literature review should check recent issues of *International Psychogeriatrics* to ensure that no review of the topic they propose to discuss has been published in the journal in recent times. Review articles may have up to 50 relevant references. Authors contemplating the submission of a literature review article are welcome to contact the editor to discuss the appropriateness of the topic prior to submission (ipaj-ed@unimelb.edu). Literature reviews should have an abstract.

"For Debate" Articles

From time to time *International Psychogeriatrics* will publish "For debate" articles on topics of a controversial nature. "For debate" articles will be commissioned by the editor, but readers are welcome to suggest possible topics for debate by contacting the editor at ipaj-ed@unimelb.edu.au. To view recently published debates see journal issues 19(6), 20(2), and 21(2).

Case Reports

Case reports will be accepted for review and considered for publication. They should be of 1200 words or less and should have no more than 10 references. An unstructured abstract of 100 words or less is required. When submitting case reports authors **must** enclose a **letter of consent to publication** from each of the patient(s) described or, if the patient(s) is/are deceased or not competent to consent the authors must indicate that they have obtained such consent from the patient's legal guardian(s). These letters will be kept confidential.

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Any author contemplating submission of a protocol only paper is advised to contact the editor of IPG via ipaj-ed@unimelb.edu.au to discuss the paper's suitability for submission prior to submitting it.

Qualitative research articles

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Supplementary Material for online only publication

International Psychogeriatrics has the facility to publish unedited figures, tables, appendices, any non-English sections, and other material which is not suitable for inclusion in papers published in

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Supply of author-generated artwork

Monochrome line subject illustrations supplied as hard copy only

These should have the author's name and figure number clearly marked on the back of each piece of artwork. The figures will be scanned at 1200 dpi and compressed using LZW. The scanning process can result in problems with some fine ornaments and with any grey tints used (e.g. tints can fill in; a Moiré interference pattern can be produced; or poor quality, patchy tints result). Illustrations of this kind may be acceptable in a desktop publishing format, but they do not proceed satisfactorily through the several stages before printing. Plain black/white is acceptable, but all other shades/tints should be replaced with distinct PostScript fills or custom fills.

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Artwork packages do not always generate pattern fills for output on image/platesetters. Imagesetters will interpret them differently from your Mac or PC and the result often looks pixellated or blocked. Where possible, use PostScript fills, custom fills and conventional tints. PostScript fills frequently do not display well on screen but they do print out correctly. It is best to avoid the use of complex or very detailed tints, patterns and symbols. These seldom reproduce satisfactorily when reduced to fit the page and when used in a caption or legend may be completely illegible when represented on a screen (for example during page make-up, or on the Web) or when output on low-quality CUP artwork instructions.doc 2 laser printers. Supplying as TIFF or EPS files (see above) alleviates this problem.

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(Revised 16/12/2015)

Manuscript preparation

1. General guidelines

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- Manuscripts should be compiled in the following order: title page (including Acknowledgments as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list). Please supply all details required by any funding and grant-awarding bodies as an Acknowledgement on the title page of the manuscript, in a separate Funding paragraph, as follows:
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Shea, J. D. (1992). Religion and sexual adjustment. In J. F. Schumaker (Ed.), *Religion and mental health* (pp. 70-84). New York: Oxford University Press. <http://www.psywww.com/psyrelig/psyrelpr.htm>

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